HEALTH LITERACY DURING AGEING AND IMPLICATIONS FOR HEALTH BEHAVIOUR

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Declaration

I, Lindsay Clare Kobayashi, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Ageing involves rising challenges for health and well-being. At the same time, older age has been associated with having low health literacy. Health literacy is essential for comprehension of the complex information that older adults need to make health decisions. Health literacy and its health behavioural outcomes during ageing have never been examined longitudinally. This thesis reviews the literature and uses data from the English Longitudinal Study of Ageing to address these gaps. Study 1, a systematic review and meta-analysis, shows that health literacy skills based on active learning may decline with age, while vocabulary-based skills are stable with age. Study 2 shows that health literacy declines in about one-fifth of English adults aged over 50 years, and that cognitive function and decline mostly explain ageing-related health literacy decline. Men, ethnic minorities, and adults with no education and in low occupational classes are the most vulnerable to losing health literacy during ageing. Study 3 demonstrates that sustained Internet use and engagement in social activities may help to prevent ageing-related health literacy decline, independently of cognitive decline. Study 4 shows that low health literacy is a barrier to participation in colorectal cancer screening, an effect mostly explained by cognitive function around the time of screening. Study 5 explores the relationships between health literacy and health behaviours over eight years, finding that health literacy may help to promote sustained regular physical activity during ageing, independently of cognitive function and physical health. Results demonstrate that health literacy is sensitive to ageing, and that cognitive function and decline play a significant role in health literacy performance at older ages. Health literacy appears to be a resource that is maintained during ageing by socially advantaged adults through specific social practices, and they use it to improve and protect their health. Limitations and future research directions are discussed.

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Chapter 1. Background to health literacy

1.1 What is health literacy?

1.1.1 A brief introduction

Health literacy is a construct with multiple, contested definitions. The working definition that will be used throughout this thesis is that developed by the Institute of Medicine (IOM) in 2004 (Institute of Medicine, 2004):

> *Health literacy is an individual's capacity to obtain, process, and understand basic health information and services sufficiently to make appropriate health decisions.*

This definition captures health literacy at a basic, functional level (i.e. 'functional health literacy') and is perhaps the most commonly used in the clinical, epidemiological, and psychological literature on health literacy.

The term 'health literacy' was coined by Scott Simonds in 1974 in a paper arguing for health education as social policy, whereby students should leave school literate in human health in a similar way as in the academic disciplines (Ratzan, 2001; Simonds, 1974). Research on health literacy slowly grew throughout the 1990s, in part sparked by the development of several measurement instruments for health literacy in the United States. In 2003, the U.S. National Assessment of Adult Literacy was released and included for the first time a nationally representative estimate of the health literacy of Americans. The report showed that over one-third of American adults had health literacy limitations, that racial inequalities in health literacy skills existed, and that adults aged 65 and over more frequently had lower health literacy than younger adults (Kutner, Greenberg, Jin, & Paulsen, 2006). This report ignited a major policy response, with the Institute of Medicine (IOM), the U.S. Agency for Healthcare Research and Quality (AHRQ), and the American Medical Association (AMA) all releasing reports on health literacy in the following year. Over the past decade, research on health literacy has grown to generate a small international field, aiming to refine the definition and measurement of the construct, to generate prevalence estimates of low health literacy, and to explore its antecedents and health-related outcomes in varying contexts and populations.

1.1.2 Defining literacy

Before examining the definition of health literacy, it is useful to step back and consider the definition of literacy. While health literacy is accepted to be ‘related to literacy’ by health literacy researchers, the definition of literacy is rarely referred to in the literature. This disconnect is surprising, given that general literacy is associated with a longer-standing and more well-established body of policy and research evidence than health literacy. A thorough understanding of what constitutes literacy may aid in developing a practical definition of health literacy. The Organization for Economic Co-operation and Development (OECD) has been conducting international literacy surveys since the mid-1990s. The titles, content, and geographical coverage of these surveys have morphed somewhat over the years; the most recent survey was conducted from 2008 to 2013 by the OECD Programme for the International Assessment of Adult Competencies (PIAAC) and is titled the Survey of Adult Skills (OECD, 2013a). As introduced in this survey, the OECD has a well-developed definition and operationalization of literacy (OECD, 2013a):

> *Literacy is defined as the ability to understand, evaluate, and engage with written texts to participate in society, to achieve one’s goals, and develop one’s knowledge and potential. Literacy encompasses a range of skills from the decoding of written words and sentences to the comprehension, interpretation, and evaluation of complex texts. It does not, however, involve the production of text (writing). Information on the skills of adults with low levels of proficiency is provided by an assessment of reading components that covers text vocabulary, sentence comprehension, and passage fluency.*

The final sentence of this passage illustrates how literacy is operationally measured by the OECD. The ‘cognitive strategies’ identified by the OECD as playing a role in literacy are those used to ‘access and identify’, ‘integrate and interpret (relating parts of text to one another)’, and ‘evaluate and reflect’ (OECD, 2013a). They state that text literacy is applicable in work-related, personal, society and community, and education and training contexts (OECD, 2013a). Here, we can see that ‘cognitive strategies’ are considered integral to literacy, and literacy is in fact referred to as a ‘cognitive skill’ and an ‘information processing skill’ throughout the OECD literature (OECD, 2013a). It is defined at a functional level in terms of using written text to aid in everyday life. Keeping this definition of literacy in mind, this chapter will next review the multiple definitions of health literacy.

1.1.3 Defining health literacy

Health literacy has multiple definitions that are contested between researchers and across disciplines. To consider 'health literacy' as a research field is to consider an intersection of the medical, epidemiological, education, health promotion, and psychological fields. The definition of health literacy that was introduced in the previous section is used by the IOM, the U.S. Department of Health and Human Services for their *Healthy People* initiative, and by researchers who are interested in health literacy in terms of basic functional or cognitive abilities such as the comprehension of written health information.

An influential alternative definition of health literacy came in 2000 from Don Nutbeam, who extended the definition beyond basic functional skills to include the cognitive and social skills that allow a person to achieve good health, and is centred on a discourse of empowerment (Nutbeam, 2000). He employs a three-pronged definition, where health literacy encompasses the following:

- **Basic/functional literacy**: sufficient basic skills in reading and writing to be able to function effectively in everyday situations, broadly compatible with being able to apply literacy skills to health related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care.
- **Communicative/interactive literacy**: more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.
- **Critical literacy**: more advanced cognitive skills, which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.

This tripartite definition of health literacy has been criticised as 'packaging new wine in old bottles' due to its claim over cognitive and social processes that have been well-researched and theorised about in the cognitive and social psychology and health promotion literatures (Tones, 2002). For example, the 1986 Ottawa Charter for Health Promotion defines health promotion as, 'the process of enabling people to increase control over and improve their health' (World Health Organization, 1986), a definition similar to that of 'critical health literacy'. The vaguely defined cognitive and social skills intrinsic to literacy in this definition are theoretically and practically separate constructs to health literacy at its most basic, which is more accurately represented by the ‘basic/functional’ literacy aspect of the definition alone. Nutbeam’s work has been valuable in incorporating literacy into the health promotion discourse, extending the concept from the narrow ‘functional’ abilities that are primarily clinical in focus. However, it has been particularly challenging to operationalize his constructs of ‘communicative’ and ‘critical’ health literacy, which is perhaps partly why they are less well researched than ‘functional’ health literacy.

A third notable definition of health literacy was developed in 2012 by the European Health Literacy Consortium and is currently used by the WHO (Kickbusch, Pelikan, Apfel, & Tsouros, 2013; Sørensen et al., 2012):

> *Health literacy is linked to literacy and entails people’s knowledge, motivation and competence to access, understand, appraise and apply health information in order make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain to improve quality of life during the life course.*

This definition was developed from a systematic review of health literacy definitions in the academic literature, which found 17 existing definitions (Sørensen et al., 2012). The review synthesised those existing definitions using a content analysis, finding six thematic clusters in the definitions of health literacy, representing: 1) competence, skills, and abilities; 2) actions; 3) information and resources; 4) objective; 5) context; and, 6) time.

These multiple and widely varying definitions have somewhat impeded health literacy as an area of inquiry. Researchers inconsistently use definitions; subsequently discourse in the field has never been cohesive. Furthermore, all definitions of health literacy have been difficult to operationalize and the existing measurement instruments often do not map onto the theoretical constructs proposed in definitions. The theoretical discourse surrounding health literacy and the constructs actually being measured become convoluted, especially for the synthesis of evidence, impeding research in this area. While recognising that there are alternative and more comprehensive definitions of health literacy, this thesis will focus on ‘functional’ health literacy as defined by the IOM.

The next section will briefly review the major theoretical frameworks of health literacy, and introduce the theoretical framework that underpins some of the empirical research in this thesis.

1.1.4 Theoretical frameworks of health literacy

A comprehensive theoretical framework of the antecedents and outcomes of health literacy was developed from Sørensen et al.’s systematic review of health literacy definitions (Figure 1.1) (Kickbusch et al., 2013; Sørensen et al., 2012). The framework was developed from Sørensen et al.’s synthesised definition of health literacy (given in the previous section), and was used to inform the development of the European Health Literacy Survey, which is discussed in Section 1.2.5.

The left-hand side of Sørensen et al.’s model highlights that ‘situational’ and ‘personal’ factors determine health literacy. Although vague on what constitutes a ‘situational’ or ‘personal’ determinant of health literacy, Sørensen et al. note that they include occupation, employment, income, social support, culture, language, environmental and political forces, and media use (Sørensen et al., 2012). Sørensen et al. also note that health literacy is determined by physical and cognitive abilities such as vision, hearing, verbal ability, memory, and reasoning, as well as social skills and meta-cognitive skills such as reading skill, reading comprehension, and numeracy (Sørensen et al., 2013).

On the right-hand side of the model, health literacy skills fall into three domains, progressing from an individual to a population perspective: *personal health care*, which includes accessing and understanding medical information and making informed decisions about health care; *disease prevention*, which includes accessing and understanding information on risk factors for health and making informed decisions about risk factors for health; and *health promotion*, which includes the ability to update oneself on the social and physical determinants of health and make decisions about the determinants of health in social and physical environments (Sørensen et al., 2012). The outcomes of health literacy skills being applied in each of these domains are variations in health service use, health costs, health behaviours, health outcomes, participation, empowerment, equity, and sustainability (Sørensen et al., 2012).

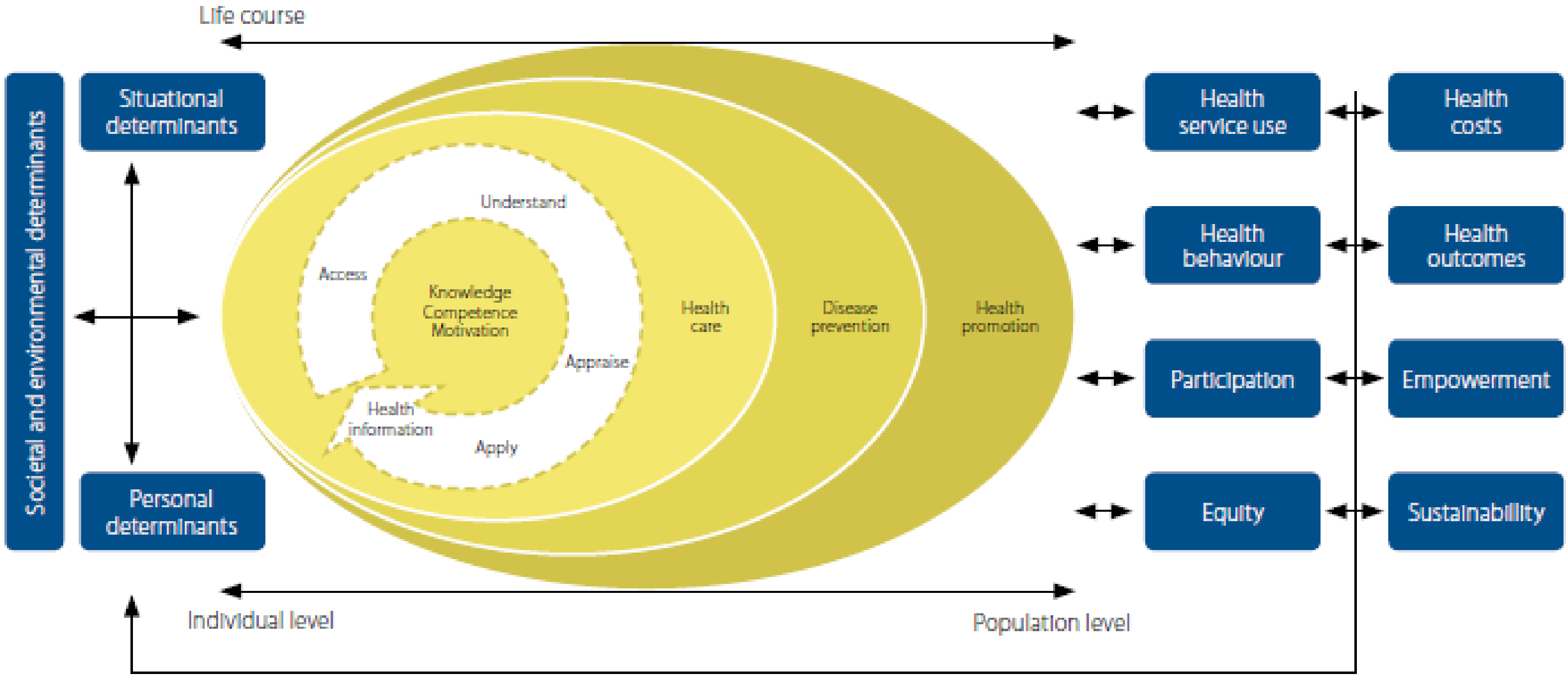

Figure 1.1 Conceptual model of health literacy from the European Health Literacy Consortium (Sørensen et al., 2013)

There is another important theoretical framework, which illustrates the antecedents and health-related outcomes of functional health literacy. The framework is broken up into two models, as a section of the original model comprising the framework was later expanded upon in more detail (Paasche-Orlow & Wolf, 2007; von Wagner, Steptoe, Wolf, & Wardle, 2009a). These two models are more straightforward than Sørensen et al.'s broad summary model; they use a more narrow definition of functional health literacy, as given by the IOM (refer to Section 1.1.1). The original model, developed by Paasche-Orlow and Wolf (2007), gives a perspective on the pathways through which limited health literacy might affect health outcomes, developed in the context of the American health care system (Figure 1.2).

Figure 1.2 Paasche-Orlow and Wolf's conceptual framework of the causal pathways linking health literacy to health outcomes

In this model, functional health literacy is determined by a myriad of social factors (race/ethnicity, education, age, occupation, income, social support, culture, and language) and sensory and cognitive functions (vision, hearing, verbal ability, memory, and reasoning). Cognitive functions, namely verbal ability, memory, and reasoning, have consistently been associated with health literacy in older adults in cross-sectional research (Federman, Sano, Wolf, Siu, & Halm, 2009; Gazmararian et al., 1999; Mõttus et al., 2014; Wolf et al., 2012). Because this this thesis focuses on the nature of changes to health literacy during ageing, the relationship between cognitive function and health literacy is an important theme that will be revisited in later chapters. On the right-hand side of this model, health literacy is thought to affect health-related outcomes through influencing three domains of health actions: access and utilisation of health care, patient-provider interaction, and self-care (Paasche-Orlow & Wolf, 2007).

This model was subsequently expanded upon to illustrate the pathways through which health literacy might affect the three domains of health actions (von Wagner et al., 2009a). Specifically, the new model expanded upon the self-care domain, re-naming it ‘management of health and illness’ to include health-promoting lifestyle behaviours as habitual self-care actions that contain an element of autonomy (Figure 1.3). On the left hand side of the expanded model, the determinants of health literacy are more broadly defined and less specific than in Paasche-Orlow and Wolf’s original model. The determinants of health literacy are divided into ‘individual’ and ‘external’ influences on health literacy. ‘Individual’ influences on health literacy include cognitive abilities, ageing-related cognitive decline, and knowledge, while ‘external’ influences include employment status, insurance coverage, family and peers, formal educational opportunities, and experiential learning (von Wagner et al., 2009a). The sum of these individual and external influences is postulated to determine a person’s health literacy level, both directly and indirectly through determining their general reading and numeracy skills.

Drawing from health psychology theory (Ajzen, 1991; Janz & Becker, 1984), the expanded framework then postulates that health literacy influences habitual health-promoting lifestyle behaviours, along with other health actions, through influencing knowledge, understanding, beliefs, and attitudes about a health action (the ‘motivational’ phase of behaviour), and implementation skills (the ‘volitional’ phase of behaviour). This part of the framework provides the theoretical underpinning for my inquiry into the role of health literacy in predicting health-promoting lifestyle behaviours in older adults. I review this part of the framework and supporting empirical evidence within the context of ageing in Chapter 4.

Figure 1.3 von Wagner et al.'s model of health literacy and health actions

1.2 Measuring health literacy

Multiple objective health literacy measurement instruments have been developed for research use. These instruments range in terms of the actual literacy and cognitive skills measured, and the degree to which they accurately reflect everyday health tasks requiring these skills. The variety of available health literacy tests somewhat reflects the myriad of health literacy definitions in use; the heterogeneity between measurement instruments contributes to general inconsistency in the field of health literacy research and often inhibits conclusions that may be drawn from reviews of low health literacy and its antecedents and outcomes.

1.2.1 The Test of Functional Literacy in Adults

The *Test of Functional Health Literacy in Adults* (TOFHLA) was developed in 1995 in the United States (Parker, Baker, Williams, & Nurss, 1995). The TOFHLA is designed to assess the functional literacy of adults using real-world health information materials in English and Spanish. Following a visual function screening test to ensure the reader has no visual difficulties that would preclude completion of the TOFHLA, the reader is presented with reading comprehension passages based on materials such as a health insurance form, X-ray preparation instructions, and a hospital consent form. There are 17 numeracy questions and 50 reading comprehension questions. The numeracy questions involve show cards with interviewer questions that require the reader to compute numerical responses using the show card information. The reading comprehension questions use the cloze procedure, where a sentence is given with a key word blanked out and the reader is asked to select from a list of four multiple choice options the correct word to fill in the blank. Examples of items from the culturally adapted UK version of the TOFHLA (the UK-TOFHLA) are shown below in Figure 1.4 (numeracy show card), Figure 1.5 (numeracy interview questions), and Figure 1.6 (reading comprehension passages) (von Wagner, Knight, Steptoe, & Wardle, 2007).

3

TORRINGTON PHARMACISTS LTD 020 8649 2235	DISP	CHKD

METHOTREXATE 2.5 MG 10/0

Take every third day.

Keep out of children's reach

Mr. IM Garfield Dr. Michael Lubin

10 11 14 31 (1 out of 10) 20 February 10

Figure 1.4 Example of a numeracy show card from the UK-TOFHLA

ASK RESPONDENT TO TURN TO CARD 3.

"Here is another direction you may be given"

GIVE THEM A FEW SECONDS TO READ THE CARD

Q3a. If you began taking your medicine on Tuesday, when should you take it next?

CODE ONE ONLY

- Monday
- Tuesday
- Wednesday
- Thursday
- **Friday**
- Saturday
- Sunday
- DK

ASK Q3b UNLESS DK AT Q3a

Q3b. What day would you take it after that?

- **Monday**
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday
- DK

(An answer which states the third day from and incorrect answer at Q3a is correct at Q3b)

Figure 1.5 Example interview questions associated with the example numeracy show card from the UK-TOFHLA

Q1. Your doctor has sent you to have a _______________ X-ray.

1a) stomach
1b) diabetes
1c) stitches
1d) germs
no answer

Q2. You must have an ______________stomach…

2a) asthma
2b) empty
2c) incest
2d) anaemia
no answer

Q3. …when you come for ______.

3a) is.
3b) am.
3c) if.
3d) it.
no answer

Q4. The X-ray will ____________....

4a) take
4b) view
4c) talk
4d) look
no answer

Q5. ….from 1 to 3 ____________ to do.

5a) beds
5b) brains
5c) hours
5d) diets
no answer

Figure 1.6 Example reading comprehension passages from the UK-TOFHLA

The final score on the TOHFLA is scaled to be out of 100. Participants are classified as having inadequate (0-59), marginal (60-74), or adequate functional health literacy (75-100). Inadequate and marginal health literacy are often grouped together to create a ‘limited’ health literacy category. The TOFHLA is also available in a short form, the S-TOFHLA (D. W. Baker, Williams, Parker, Gazmararian, & Nurss, 1999); these two tests are perhaps the most commonly used measurement instruments in research. The TOFHLA takes 22 minutes to administer and the S-TOFHLA 7 minutes, which renders them difficult to use in clinical settings. Both tests are probably the most comprehensive health literacy assessments available, although they do not distinguish between reading ability, prior familiarity with health materials, and cognitive skills such as short-term memory and reasoning as applied in medical settings. However, one may argue that these are all interrelated aspects of health literacy and cannot or should not be theoretically or practically separated. The TOFHLA has been culturally adapted to the UK context (the UK-TOFHLA) (von Wagner et al., 2007) and translated into several languages including French, Italian, German, Korean, and Portuguese (Carthery-Goulart et al., 2009; Connor, Mantwill, & Schulz, 2013; Kim, 2009).

1.2.2 The Newest Vital Sign

The *Newest Vital Sign* (NVS) was developed in 2005 as a brief assessment that captures the functional reading abilities required for health literacy (Weiss et al., 2005). It is intended as a screening tool to identify patients in health care settings who may have low health literacy. It was validated against the TOFHLA. In the NVS, an ice cream nutrition label is presented to the reader, who is then given six questions assessing reading comprehension, numeracy, and the ability to reason and apply the information to hypothetical personal health situations. It is scored out of six points. The NVS has high sensitivity, with scores <4 having 100% sensitivity for predicting limited health literacy (TOFHLA score <75), but low specificity, with scores <4 having 64% specificity for predicting limited health literacy. Hence, the NVS may overestimate the proportion of people who have limited health literacy. Benchmarked against the TOFHLA, participants are scored as having a ‘greater than 50% chance of having marginal or inadequate health literacy’ (NVS score of <2), as ‘possibly’ having limited health literacy (NVS score of 2-4), or as having ‘adequate’ health literacy (NVS score of >4). The NVS takes three minutes to administer and was developed in English and Spanish, and has been culturally adapted to the UK (the NVS-UK) (Rowlands et al., 2013). Reproduced from Rowlands et al. (2013), the NVS-UK show card is shown below in Figure 1.7 and the associated interview questions and answers in Table 1.1.

Product Description: Ice Cream		
Serving Size:	100ml	
Servings per container:	4	
NUTRITIONAL INFORMATION		
TYPICAL VALUES		***Per 100ml***
Energy		**1050 kJ**
		250 kcal (calories)
Protein		**4 g**
Carbohydrate		**30 g**
of which sugars		23 g
Fat		**13 g**
of which saturates		9 g
of which monounsaturates		0 g
of which polyunsaturates		3 g
of which trans fats		1 g
Fibre		**0 g**
Sodium		**0.05 g**

Ingredients: Cream, Skimmed Milk, Sugar, Whole Egg, Stabilisers (Guar Gum), Peanut Oil, Vanilla Extract (0.05%).

Figure 1.7 Show card from the UK-NVS

Table 1.1 NVS-UK questions and correct responses (from Rowlands et al., 2013)

Interview question	Correct response
1. How many calories (kcal) will you eat if you eat the whole container?	1,000 KCAL or 1,000 calories
2. If you are advised to eat no more than 60 grams of carbohydrate for dessert, what is the maximum amount of ice cream you could have?	Two servings (or anything up to two servings) OR Half the container (or any amount up to half the container) OR 200 mL (or any amount up to 200 mL).
3. Imagine that your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, some of which comes from one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be eating each day?	33 g
4. If you usually eat 2500 calories each day, what percentage of your daily calorie (kcal) intake will you get if you eat one serving of ice cream?	1/10 (one tenth) OR 10%
Read out: Imagine that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.	
5. Is it safe for you to eat this ice cream?	No
If 'no' at 5:	
6. Why not?	Because it contains peanut oil/peanuts/nuts OR Because you might have an allergic reaction
*Ask IF answer to Q6 is '*Because you might have an allergic reaction'	
7. Why would you have an allergic reaction?	Because it contains peanut oil/peanuts/nuts

1.2.3 The Rapid Estimate of Adult Literacy in Medicine

The *Rapid Assessment of Adult Literacy in Medicine* (REALM) was developed in 1993 as a test of medical word recognition (Davis et al., 1993). The reader is presented with a list of 66 medical words ranging from ‘flu’, ‘fat’, and ‘pill’ to ‘obesity’, ‘osteoporosis’, and ‘impetigo’, and is required to read them aloud to the administrator. Participants are classified to an equivalent reading level based on REALM score: 3rd grade (0-18), 4-6th grade (19-44), 7-8th grade (45-60), or ≥9th grade (61-66). The REALM is brief, at 3 minutes to administer, although it measures no more than medical-related vocabulary, word recognition, and pronunciation. Reading comprehension, reasoning and judgement skills, and information navigation skills are not captured by the REALM. The REALM has been frequently used in research due to its advantage of brevity, although researchers are often more in favour of the TOFHLA due to its increased comprehensiveness. The REALM has been adapted into two short versions: the REALM-SF and the REALM-R (Arozullah et al., 2007; Bass, Wilson, & Griffith, 2003). The REALM is shown below in Figures 1.8 and 1.9.

Figure 1.8 The REALM interviewer instructions

Figure 1.9 The medical words included in the REALM

1.2.4 The OECD International Literacy Surveys

The first of the OECD international literacy surveys, the *International Adult Literacy Survey* (IALS), was conducted from 1994 to 1998. It was undertaken jointly with Statistics Canada with the interest of characterising the functional abilities of adults in the increasingly knowledge-based marketplaces of the OECD region (OECD, 2013b). The second generation of this survey, titled the *International Adult Literacy and Life Skills* survey (IALLS), was conducted from 2002 to 2006 and was expanded to include health literacy as a required skill set for daily functioning (OECD, 2013b). Health literacy questions were developed for this survey using a 2003 United Nations Educational, Scientific, and Cultural Organization (UNESCO) framework that defined literacy as:

> *The ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning to enable an individual to achieve his or her goals, to develop his or her knowledge or potential, and to participate fully in the wider society.*

Therefore, health literacy items in the IALLS were developed within a goal-based health context. The IALLS instrument assesses prose, document, and quantitative literacy in three health domains: clinical, prevention, and navigation of the health care system (Kutner et al., 2006). The clinical domain includes tasks such filling out a patient information form for an office visit and understanding dosing instructions for medication. The prevention domain includes tasks such as following guidelines for age-appropriate preventive health services and understanding how eating and exercise habits decrease risks for developing serious illness. The navigation domain includes tasks such as understanding what a health insurance plan will and will not pay for and being able to give informed consent for a health care service.

The most recent iteration of the OECD international literacy survey was conducted from 2011 to 2012, and was titled the *Survey of Adult Skills* (a product of the Programme for the International Assessment of Adult Competencies, or PIAAC; also reviewed in Section 1.1.2). This survey uses the same definition of literacy and similar methods of assessing literacy as the previous surveys, except that prose and document literacy were analysed as a single measure rather than separate measures. This survey additionally measured information technology use skills, such as navigating the Internet, filling out online forms, and using email, as these skills are becoming increasingly important in knowledge- and technology-based economies worldwide (OECD, 2013a).

One item from the clinical domain of the IALLS was used in the English Longitudinal Study of Ageing (ELSA) (NatCen Social Research, 2012). The item consists of a hypothetical medicine label similar to that found on a bottle of aspirin, with four interviewer-administered reading comprehension questions relating to medicine dosing and contraindications (Figure 1.10). This item is the measure that was used to assess functional health literacy in the empirical chapters of this thesis that use the ELSA data.

MEDCO TABLET

INDICATIONS: Headaches, muscle pains, rheumatic pains, toothaches, earaches.
RELIEVES COMMON COLD SYMPTOMS

DOSAGE: ORAL. 1 or 2 tablets every 6 hours, preferably accompanied by food, for not longer than 7 days. Store in a cool, dry place.

CAUTION: Do not use for gastritis or peptic ulcer. Do not use if taking anticoagulant drugs. Do not use for serious liver illness or bronchial asthma. If taken in large doses and for an extended period, may cause harm to kidneys. Before using this medication for chicken pox or influenza in children, consult with a doctor about Reyes Syndrome, a rare but serious illness. During lactation and pregnancy, consult with a doctor before using this product, especially in the last trimester of pregnancy. If symptoms persist, or in the case of an accidental overdose, consult a doctor. Keep out of reach of children.

INGREDIENTS: Each tablet contains
500 mg acetylsalicylic acid.
Excipent c.b.p 1 tablet
Reg. No. 88246

Made in Canada by STERLING PRODUCTS. INC
1600 Industrial Blvd. Montreal, Quebec H9J 3P1

Figure 1.10 The IALLS/ELSA health literacy measure

The four reading comprehension questions that accompany the measure are questions that one should be able to correctly answer in order to take the medication properly, and are as follows:

1. *What is the maximum number of days that you may take this medicine?*
2. *List three situations for which you should consult a doctor*
3. *List one condition for which you might take the Medco tablet*
4. *List one condition for which you should not take the Medco tablet*

These questions, the correct answers, and the instructions given to the study interviewers in the ELSA will be elaborated upon in the Methods section of Chapter 8, which presents the first empirical study of this thesis that uses the ELSA data.

1.2.5 The European Health Literacy Project (HLS-EU)

The European Health Literacy Project (HLS-EU) was conducted from 2009 to 2012 as a Maastricht University-led consortium of nine institutions from Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland, and Spain. The HLS-EU-Q takes a citizen empowerment approach to measuring health literacy, with a focus on how health literacy affects quality of life throughout the life course (Sørensen et al., 2013). This perspective is in contrast to the clinical focus of the American methods of measuring functional health literacy. The HLS-EU developed a novel instrument for assessing health literacy at the population level, for use in the European Health Literacy Survey (HLS-EU-Q). The HLS-EU-Q is based on the conceptual framework of health literacy from Sørensen et al., described in Section 1.1.3. From Sørensen's framework, the HLS-EU-Q aims to measure self-reported skills in each of a) accessing, b) understanding, c) appraising, and d) applying health-related information across the domains of 1) healthcare, 2) disease prevention, and 3) health promotion (Sørensen et al., 2013). Hence, the content of the questionnaire can be laid out in a 12 cell matrix. All of the questions in the HLS-EU-Q are subjective questions about the ease or difficulty of performing specific tasks, such as *'On a scale from very easy to very difficult, how easy would you say it is to understand why you need health screenings?'* (Sørensen et al., 2013). The self-report nature of the HLS-EU-Q has generated a great deal of criticism from proponents of the objective functional health literacy measures.

1.2.6 Other measures

There is a range of health literacy measures that have been developed for various purposes, but have not been adopted widely. Some are intended for particular patient populations, such as a measure of functional, communicative, and critical health literacy for diabetes patients (Ishikawa, Takeuchi, & Yano, 2008). This measure is interesting, as it appears to be a rare attempt at a brief measure that captures all three aspects of Nutbeam's tripartite health literacy definition. In the 'functional' domain, the measure assesses the extent to which patients had experienced difficulties in reading the instructions or leaflets from hospitals and pharmacies; in the 'communicative' domain, the measure assesses the extent to which patients had extracted and communicated diabetes-related information since being diagnosed; in the 'critical' domain, the measure assesses the extent to which patients had critically analysed the information and used it to make decisions. Like the HLS-EU-Q, the measure is self-report in nature and each domain was assessed by four or five agree/disagree statements, such as *'Since being diagnosed with diabetes, you have communicated your thoughts about your illness to someone'* (communicative domain) (Ishikawa et al., 2008). The degree to which the measure actually captures Nutbeam's three domains is debatable, but the intent is valuable as few measures capture communicative and critical aspects of health literacy.

Other measures include the Cancer Message Literacy Test (Mazor et al., 2012), the Short Literacy Survey (Dageforde et al., 2015), the Health Literacy Assessment Scale for Adolescents (Manganello, Devellis, & Davis, 2015), the Health Literacy Skills Instrument (Bann, McCormack, Berkman, & Squiers, 2012), and the Health Literacy Questionnaire (HLQ) (Beauchamp et al., 2015). The HLQ is notable, as it is the measurement vehicle of the new OPHELIA Project (Optimising Health Literacy to Improve Health and Equity), which aims to identify local health literacy needs and co-develop appropriate interventions with the community stakeholders (Deakin University, 2015; Batterham et al., 2014). The HLQ is a self-reported assessment of health literacy that was validated through consultations with clinical, public health, governmental, and community stakeholders (Batterham et al., 2014). The OPHELIA Project has just begun and could potentially be very valuable for improving health outcomes and also in reconceptualising popular definitions and approaches to health literacy.

1.3 Summary

This chapter reviewed the major definitions of health literacy, the major theoretical frameworks used to illustrate the determinants and health-related outcomes of health literacy, and the measurement tools used to assess health literacy in research. The main finding is that health literacy is defined and measured in several disparate ways. The measurement instruments that dominate the literature are the TOFHLA, the REALM, and the NVS, which are based on a definition of health literacy as 'functional' cognitive and reading comprehension skills, as applied in mostly clinical settings. More recently, subjective measures that aim to be more holistic and contextual have emerged and are embedded within a health promotion perspective. Whether these two broad clinical-based and health promotion-based 'camps' of health literacy research can be brought together and integrated is uncertain. The 'health promotion' turn in health literacy research is gaining more and more traction over time, with the development of projects such as the HLS-EU and the OPHELIA Project.

Empirically, the focus of this thesis will be on the most basic 'functional' level of health literacy, including reading comprehension, basic numeracy, vocabulary, and reasoning in health-related settings. Although the concept of functional health literacy does not fully capture the more advanced cognitive and social competencies required for personal health management, it is consistently and independently associated with several health outcomes among older adults, including all-cause mortality (D. W. Baker, Wolf, Feinglass, & Thompson, 2008; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Bostock & Steptoe, 2012; Sudore et al., 2006). Among the different definitions of health literacy, functional health literacy is also the best operationally represented by the measurement instruments that are most commonly used in research to date. Although I recognise that health literacy is often considered to include more than just functional skills, I will hereafter use the terms 'functional health literacy' and 'health literacy' interchangeably throughout this thesis, for ease of reading.

Chapter 2. The epidemiology of limited health literacy

The previous chapter reviewed the major definitions of health literacy, the major conceptual frameworks used to illustrate the determinants and health-related outcomes of health literacy, and the measurement tools used to assess functional health literacy in research studies. Now, this chapter will review the epidemiology of limited health literacy. It will describe the population prevalence of low health literacy in England and elsewhere, and will review the major sociodemographic and cognitive factors that are associated with limited health literacy.

2.1 The prevalence of limited health literacy

Population prevalence estimates of limited health literacy vary in terms of the instruments used to assess health literacy and in their completeness across age groups. Many countries have population estimates for general literacy, but not for health literacy; subsequently this section will also include population prevalence estimates of low general literacy where health literacy measures are not available. This chapter will focus on England and similar Western countries, so that estimates are comparable. General population literacy estimates are available for England, while health literacy estimates are available for adults in Canada, the United States, some European countries, and adults aged 52 years and over in England.

2.1.1 England

In England, no nationally representative estimate for the overall population prevalence of limited health literacy exists. However, a survey entitled *Skills for Life* was commissioned by the Department for Education and Skills to establish a nationally representative profile of adult literacy, numeracy, and information and communications technology (ICT) skills (J. Williams, Clemens, Oleinikova, Tarvin, & BMRB Social Research, 2003). The survey has now been conducted twice among adults aged 16 to 65 years, in 2002 and in 2011. In 2011, 28.5% of the adult population had ‘Level 1’ literacy, which is equivalent to an English GCSE at grades D-G, and 56.6% had ‘Level 2 or above’ literacy, equivalent to an English GCSE at grades A*-C (Harding et al., 2012). However, 14.9% of the population was found to have a literacy level of ‘Entry level 3 or below’ according to the National Qualifications Framework (Harding et al., 2012). These adults would not be able to pass an English GCSE and would have literacy levels at or below what is expected of an 11 year-old, and therefore are considered ‘functionally illiterate’.

Unfortunately, adults aged over 65 were not included in the *Skills for Life* survey, so there is no indication of literacy levels among this age group in England. With respect to health literacy, the focus of this thesis, there is a somewhat representative existing estimate from the English Longitudinal Study of Ageing (ELSA). Approximately one-third of adults aged 52 and over in the ELSA obtained a less than perfect score on the health literacy assessment in the ELSA in 2002 (Bostock & Steptoe, 2012). The assessment came from the OECD IALLS (reviewed previously in Chapter 1), and was a four-item reading comprehension test of a fictitious medicine label; any score less than perfect would indicate difficulties in proper taking of a prescription medication. In sum, about one-third of English adults aged 52 and over has difficulty comprehending a medicine label (i.e. has limited health literacy), encompassing the 15% or more of English adults aged 65 and over who would be expected to be functionally illiterate.

2.1.2 Other countries

Because no nationally representative prevalence estimate of low health literacy exists for England, aside from the reasonably representative estimate for adults aged 52 years and over in the ELSA, national prevalence estimates for low health literacy in select European countries, the United States, and Canada are reviewed in this section.

Using the HLS-EU-Q instrument that was described in Chapter 1, population-based health literacy estimates, based on a subjective assessment, are available for adults aged 15 years and over in eight countries in Europe: Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland, and Spain (Sørensen et al., 2015). Four levels of subjective health literacy were defined: 'insufficient', 'problematic', 'sufficient', and 'excellent'. The survey showed that at least 1 in 10 (12%) of respondents reported having 'insufficient' health literacy, and almost 1 in 2 (47%) reported 'problematic' health literacy (Sørensen et al., 2015). The distribution of subjective health literacy levels varied widely across countries, with the Netherlands having only 1.8% of respondents having 'insufficient' health literacy and Bulgaria having 26.9% of respondents having 'insufficient' health literacy (Sørensen et al., 2015).

Using slightly different scoring systems in each country, the *International Adult Literacy Survey* (IALS) in North America found that 36% of Americans and 60% of Canadians aged 16 and over had the lowest levels of health literacy (Canadian

Council on Learning, 2008; Kutner et al., 2006). Both countries used the same data from the IALS, where health literacy was scored on a scale from 0 to 500, and then categorised into five levels. The figure for Americans refers to the percentage of adults who scored as having *Below Basic* (14%; score of 0-184) or *Basic* (22%; score of 185-225) health literacy (Kutner et al., 2006). Just over half of adults had *Intermediate* health literacy (53%; score of 226-309), and only 12% had *Proficient* health literacy in this survey (score of 310-500). Adults at the *Below Basic* level range from being illiterate in English to being able to locate easily identifiable information in short, commonplace prose texts and simple documents. At the *Basic* level, adults should be able to read and understand information in short, commonplace prose texts and simple documents. The *Intermediate* and *Proficient* levels include more complex and challenging tasks, such as reading and understanding dense, less commonplace prose texts and documents, and making inferences about information (Kutner et al., 2006). The proportion of Canadians classified as lacking health literacy is higher than the proportion of Americans, as the cut-points equivalent to *Basic* and *Below Basic* are higher (0-225 and 226-275, respectively), giving a more liberal definition of low health literacy.

2.2 Sociodemographic predictors of limited health literacy

This section will review the sociodemographic predictors of limited health literacy. The antecedents of health literacy that are outlined in Paasche-Orlow and Wolf and von Wagner et al.'s theoretical models of functional health literacy inform this section. The predictors that will be reviewed are: age, cognitive function, educational attainment, gender, ethnicity, and other socioeconomic indicators. Although it is not a sociodemographic factor, the role of cognitive function in health literacy will be briefly introduced, as cognitive function is thought to explain the effect that age may have on health literacy.

2.2.1 Age

This sub-section introduces and only briefly narratively reviews the association between age and health literacy in older adults, as the first empirical chapter of this thesis aims to quantify this relationship through a systematic review and meta-analysis of the existing literature.

Older adults have frequently been found to perform more poorly on health literacy tests than younger adults in cross-sectional research, mostly among samples of patients and Medicare enrolees in the United States (D. W. Baker, Gazmararian, Sudano, & Patterson, 2000; D. Baker et al., 2002; Calkins Aguirre, Ebrahim, & Shea, 2005; von Wagner et al., 2007; M. Williams, Baker, Parker, & Nurss, 1998). A 2005 systematic review of 85 American studies found that older age was consistently associated with having lower health literacy (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). Specifically, studies with an average sample age of less than 50 years had a mean prevalence of low health literacy of 15.9% (95% CI: 7.7%–24.1%), while studies with an average age of over 50 years had a mean prevalence of 37.9% (95% CI: 31.6%–44.2%) (Paasche-Orlow et al., 2005). According to the IALS in North America, over 70% of adults aged over 65 years are estimated to have limited health literacy (Canadian Council on Learning, 2008; Kutner et al., 2006). Older age was also associated with lower subjective health literacy across eight countries in Europe in the HLS-EU-Q (Sørensen et al., 2015). Across the OECD countries, older adults had lower general literacy, numeracy, and technology use skills than younger adults. The authors noted that the age gap varied widely between countries, concluding that policy and contextual differences between countries may impact the effect of age on information use skills (OECD, 2013a).

Longitudinal, within-person evidence for the association between age and health literacy is lacking. It is unclear whether the cross-sectional relationship between age and health literacy is due to a cohort effect, or whether there is something inherent to the ageing process that results in a loss of literacy skills. For example, differences in educational experiences and usage of literacy-promoting technologies across generations may explain the broad age differences in health literacy skills (Selwyn, Gorard, Furlong, & Madden, 2003; Zickuhr, 2013); but, the cognitive changes experienced during ageing may bring about intra-individual changes in health literacy over time (Federman et al., 2009; Wolf et al., 2012). This thesis will be among the first to use longitudinal data to investigate whether health literacy declines over time during ageing, in addition to the roles of cognitive function and decline in any potential health literacy decline, and, the health behavioural outcomes of low and declining health literacy during ageing.

2.2.2 Cognitive function

An individual factor that is possibly involved in the relationship between age and health literacy is cognitive function. The negative relationship between age and health literacy may be at least partly mediated by cognitive function (Deary et al., 2009; Kobayashi et al., 2015; Richards & Sacker, 2010). Older adults often experience ageing-related non-pathological decline in cognitive function (i.e. cognitive ageing), which would negatively affect performance on tests of health literacy (Dahlke, Curtis, Federman, & Wolf, 2014; Federman et al., 2009; Mõttus et al., 2014; Murray, Johnson, Wolf, & Deary, 2011; Wolf et al., 2012). This relationship will be the focus of Chapter 3 and will be a recurring theme throughout the empirical chapters of this thesis. It is useful to introduce the concept of cognitive function here, in light of its important relationship with health literacy.

The three concepts of cognitive function, cognitive ability, and intelligence are worth defining and delineating at this point. Cognitive function is a term used to collectively refer to the range of cognitive functions that are involved in the input, storage, processing, and output of information (Singh-Manoux, 2010). Examples of cognitive functions include working memory, prospective memory, verbal fluency (including both of semantic fluency, which is the recall of categories of words, such as animal names, and phonemic fluency, which is the recall of phonemically similar words, such as words starting with the letter ‘p’), inductive reasoning, and mental processing speed (Wolf et al., 2012). In contrast, cognitive ability and intelligence are terms used interchangeably to refer to the concept of a single, unitary, and heritable general intelligence (operationally referred to as *g*) (Calvin, Batty, & Deary, 2011; Deary & Batty, 2007; Gould, 1996; Hernstein & Murray, 1994). General intelligence is tested psychometrically by standardised mental (IQ) tests, such as the Stanford-Binet IQ test or Moray House No. 12 IQ test (Deary & Batty, 2007).[1]

The traditional conceptualisation of general intelligence (*g*) obscures the multiplicity of cognitive functions that may have differential amenability to change over time and effects on health outcomes (Sabia et al., 2010). The construct *g*, which is the first unrotated principal component of a factor analysis of multiple tests of cognitive functions, consistently explains only about 50% of the variance in performance on individual cognitive function tests (Gould, 1996; Nooyens, van Gelder, & Verschuren, 2008; Sabia et al., 2010; Salthouse, 2001). Hence, something other than the operational construct of ‘intelligence’ explains people’s performances on the tests of cognitive functions that are meant to represent intelligence. A recent

[1] The theory and measurement of general intelligence is outside of the scope of this thesis, although further reading can be found in ‘The Bell Curve: Intelligence and Class Structure in American Life’ by Richard J Hernstein and Charles Murray (Simon & Schuster Ltd, New York: 1996) and ‘The Mismeasure of Man: The Definitive Refutation to the Argument of *The Bell Curve*’ by Stephen Jay Gould (W. W. Norton & Co., New York: 1996).

analysis of the Whitehall II cohort did not support the empirical use of a unitary intelligence construct (*g*), at least with respect to prediction of mortality risk, as the specific cognitive domains of memory and reasoning predicted mortality risk, while the reduced *g* measure did not (Sabia et al., 2010). This thesis will consider individual cognitive functions to examine their specific roles in affecting health literacy, rather than a reduced *g* measure of generalised intelligence.

2.2.3 Educational attainment

Educational attainment is consistently and strongly associated with health literacy (D. W. Baker, Parker, Williams, & Clark, 1998; Bostock & Steptoe, 2012; Calkins Aguirre et al., 2005; Canadian Council on Learning, 2008; Federman et al., 2009; Gazmararian et al., 1999; Kutner et al., 2006; Levinthal, Morrow, Tu, Wu, & Murray, 2008; Miller, Brownlee, McCoy, & Pignone, 2007; Morrow et al., 2006; Rowlands et al., 2013; von Wagner et al., 2007). Despite this link, it is important to note that health literacy is not simply a proxy variable for educational attainment. Theoretically, health literacy can be imparted through experiences outside of education such as increasing familiarity with the medical system and learning from health information. Experiential learning is in fact included as a determinant of health literacy in von Wagner et al.'s (2009) conceptual framework, separately from formal educational experiences. Empirically, daily reading was shown to be the single strongest predictor of health literacy in the *International Adult Literacy and Life Skills* survey (IALLS) in Canada (Canadian Council on Learning, 2008) and daily newspaper reading has been shown to be a strong predictor of health literacy independently of education and other sociodemographic factors among adults aged 65 and over (D. W. Baker et al., 2000). Health literacy shows explanatory power for health outcomes independently of education, further indicating that it is not a simple proxy variable for educational attainment (I. M. Bennett, Chen, Soroui, & White, 2009; Bostock & Steptoe, 2012; S.-Y. D. Lee, Arozullah, Cho, Crittenden, & Vicencio, 2009; von Wagner et al., 2007; Wolf et al., 2012).

2.2.4 Gender

There should be no inherent reason why health literacy would differ by gender; any gender differences in health literacy would likely be due to social, educational, economic, or political conditions that may differentially affect the development of literacy skills between men and women (Harding et al., 2012). In empirical research, gender appears to be inconsistently associated with health literacy. Some studies have found women to perform better on health literacy tests than men (D. W. Baker et al., 2000, 1998; Calkins Aguirre et al., 2005; Morrow et al., 2006; Rowlands et al., 2013; von Wagner et al., 2007), while others have found no difference between genders (Bostock & Steptoe, 2012; Levinthal et al., 2008; Miller et al., 2007). In a systematic review of 85 studies in the US, health literacy did not differ by gender (Paasche-Orlow et al., 2005).

In Europe, men had slightly worse self-rated health literacy than women (Sørensen et al., 2015). In Canada and the United States, women performed marginally, but not significantly better than men on the health literacy component of the *International Adult Literacy and Life Skills* survey (Canadian Council on Learning, 2008; Kutner et al., 2006). In the US, 16% of men vs. 12% of women in the survey were classified as having below basic literacy skills (Kutner et al., 2006). In the UK, there are no gender differences in overall literacy: 45% of men and 44% of women were classified as having Level 2 or higher (GCSE at grades A* to C or above) literacy in the 2002 *Skills for Life* Survey (J. Williams et al., 2003). In the ELSA, older English men and women have equal health literacy skills (Bostock & Steptoe, 2012).

2.2.5 Ethnicity

'Race' and ethnicity are also inconsistently associated with health literacy across studies and countries. In the United States, 41% of Hispanics have below basic health literacy, compared to 25% of American Indian/Alaska Natives, 24% of Blacks, 13% of Asian/Pacific Islanders and only 9% of White Americans (Kutner et al., 2006). In Canada, Aboriginals living off reserve lands and linguistic minorities have lower health literacy scores than the national average (Canadian Council on Learning, 2008).

In the ELSA, health literacy does not differ by ethnicity, assessed as 'white' vs. 'not white' (Bostock & Steptoe, 2012). Less than 3% of the ELSA study population is 'not white', partly reflecting the sociodemographic composition of older England's population where 96% of adults aged ≥50 years were of a 'White British', 'White Irish', or 'White Other' background in the 2001 Census (UK Data Service Census Support, 2001). The ELSA, while population-representative of ethnicity in this age group, therefore has low statistical power to investigate the ethnic differences in health literacy. In another study of 803 adults from South London with coronary heart disease, adults from a Black and Minority Ethnic (BME) group were more than twice as likely to have low health literacy as adults who identified as White British (30% vs. 13%) (Rowlands et al., 2013).

In the UK *Skills for Life* survey, White British respondents performed the best, with 46% achieving Level 2 literacy or above (GCSE at grades A* to C or above) (J. Williams et al., 2003). Although all BME groups scored more poorly than White British respondents (39% of Asian Indians, 23% of Asian Pakistani, 26% of Black Caribbean, and 24% of Black African scored at Level 2 or above), excluding all BME individuals who did not speak English as a first language completely removed the ethnic group differences in literacy skills, with one exception (J. Williams et al., 2003). The exception was for Black Caribbean respondents, who mostly spoke English as a first language and still had lower literacy scores than White British respondents (J. Williams et al., 2003). Hence, the relationship between English literacy and ethnicity is mostly explained by English language proficiency. The underlying causes of any racial or ethnic differences in health literacy in the United Kingdom have not been investigated.

2.2.6 Other socioeconomic indicators

Health literacy skills are disparate by several other indicators of socioeconomic position. Comparing across nations, the OECD PIAAC survey found that greater inequality in literacy skills is correlated with greater inequality in income (OECD, 2013a). In other words, countries that have large income gaps also tend to have large literacy gaps. In Canada, the geographic distribution of health literacy skills reflects the classic 'east-west' geographic gradient in health, where adults living in the western part of the country have better health status and longer life expectancy than those living in the east (Canadian Council on Learning, 2008; Gaudette, Altmayer, Wysocki, & Gao, 1998; Millar, 1995). This gradient is somewhat analogous to the classic 'north-south' divide in health in England, where adults in the north typically have lower life expectancy than those in the south (Newton et al., 2015). Health literacy is also graded by levels of multiple deprivation across neighbourhoods within cities, where low health literacy is more frequent in deprived neighbourhoods (Canadian Council on Learning, 2008). In the United States, adults living below the poverty level had the lowest health literacy, and mean health literacy scores increased in a graded fashion with income (Kutner et al., 2006). Low health literacy has been associated with low income in the US and UK (Bostock & Steptoe, 2012; Federman et al., 2009; Gazmararian et al., 1999; von Wagner et al., 2007), and with financial vulnerability in Europe, such as having problems paying bills

(Sørensen et al., 2015). In Canada, unemployed adults have substantially lower health literacy than employed adults (Canadian Council on Learning, 2008). Low health literacy has also been associated with lack of car ownership in the US (D. W. Baker et al., 1998), lower occupational class in the US and UK (Bostock & Steptoe, 2012; Gazmararian et al., 1999), low income in the US and UK (Kutner et al., 2006; von Wagner et al., 2007) and residing in a neighbourhood with a high level of multiple deprivation in the UK (Rowlands et al., 2013).

2.3 Summary

Although nationally representative data on health literacy skills in England are lacking, low health literacy appears to be an important public health problem in several other countries. About 15% of adults aged 16-65 years are functionally illiterate in England, and, given the apparent inverse association between age and literacy, this proportion may be even higher among adults aged over 65 years. Data from the English Longitudinal Study of Ageing show that approximately one-third of adults aged 52 and over have limited health literacy in England. Internationally, there are wide differentials between and within countries in the prevalence of low health literacy. The prevalence depends partly on the measurement method used to assess health literacy and the demographic compositions of the samples used in literacy surveys.

Further research on the epidemiology of health literacy in the older UK population is required. Based on the cross-sectional evidence already in existence, it appears that health literacy is strongly graded by age, ethnicity, education, and multiple indicators of deprivation. Health literacy does not appear to differ by gender, and low health literacy in BME groups appears to be mostly explained by English language proficiency problems. Therefore, those adults who are often vulnerable to health inequalities also experience literacy barriers to health self-management, which may further create and reproduce social inequalities in health. Health literacy is particularly important for older adults as health services such as cancer screening become available, and preventive lifestyle behaviours become increasingly important when the risks increase for chronic diseases, multiple morbidities, and declining physical and cognitive function.

Therefore, understanding the trajectories and determinants of health literacy skills during ageing and the influence of health literacy on health behaviours among older adults is essential for reducing literacy-based barriers to health during ageing.

Whether low or declining health literacy has an influence on engagement in health-promoting behaviours over and above other changes that often take place during ageing, such as physical and cognitive decline and social and economic changes, is unknown. Further, just as the dynamics of changes to health literacy skills during ageing are unknown, the risk factors for decline in health literacy skills during ageing are unknown. Two key ageing-related factors that may affect health literacy that will be addressed in-depth in this thesis are reduced cognitive function and ageing-related cognitive decline.

Chapter 3. Ageing, cognitive function, and health literacy

The previous chapter demonstrated that, in addition to socioeconomic indicators, older age is one of the main predictors of limited health literacy in existing cross-sectional research. Cognitive function, which tends to undergo non-pathological decline in several domains during ageing, is also closely related to health literacy. Therefore, cognitive function and ageing-related cognitive decline are particularly important to consider as explanatory factors when examining longitudinal changes to health literacy during ageing, as this thesis will investigate. This thesis will consider individual cognitive functions, rather than a unitary construct of general intelligence (*g*), based on evidence that individual cognitive functions have differential relationships with health outcomes, and on evidence that individual cognitive functions have differential relationships with functional health literacy (Kobayashi et al., 2015; Singh-Manoux, 2010; Wolf et al., 2012). This chapter will review the existing evidence describing ageing-related cognitive decline (i.e. cognitive ageing), changes to general literacy skills during ageing, and the relationship between cognitive function and health literacy in older adults.

3.1 Cognitive ageing

Non-pathological declines in cognitive function (i.e. cognitive ageing) tend to occur progressively with increasing age (Salthouse, 2009). The rate of decline appears to accelerate with increasing age, although the degrees and rates of cognitive ageing vary greatly between individuals (R. S. Wilson et al., 2002). Although all cognitive functions typically develop in concert and development in one area can reflexively help further development in another area, cognitive function has been roughly divided into two types: *fluid cognitive functions* (also known as *cognitive mechanics*) and *crystallised cognitive functions* (also known as *cognitive pragmatics*). Similarly, the concept of general intelligence is dichotomised into fluid (*gf*) and crystallised (*gc*) domains (Deary & Batty, 2007; Horn, 1994). Fluid cognitive functions are defined as those involved in active learning independently of prior knowledge or skills, such as executive function, inductive reasoning, short-term verbal memory, mental processing speed, semantic fluency, and phonemic fluency (Deary et al., 2009). These fluid skills have been observed in longitudinal research to begin declining around age 45 in men and women, although decline may begin even earlier (Deary et al., 2009; O'Carroll, 1995; Singh-Manoux et al., 2012). Crystallised cognitive functions are defined as vocabulary, numerical skills, and generalised knowledge, which are developed over the entire life course and show little, if any age-associated, decline (Deary et al., 2009; O'Carroll, 1995; Singh-Manoux et al., 2012).

Fluid and crystallised cognitive functions are built up in early life, during childhood and adolescent development. The neurological maturation of the brain is thought to play a more dominant role in the development of fluid cognitive functions, while experiential factors are thought to have greater influence over crystallised cognitive functions (Deary & Batty, 2007). Factors such as parental investment in learning, type and quality of education, and the regular practice of cognitive, numerical, and literacy skills influence the development of ability in both areas. Father's occupation, a marker of childhood socioeconomic circumstances, has been shown to independently influence childhood cognitive function as early as 22 months (Feinstein, 2003); the effect of childhood socioeconomic circumstances on cognitive reserve appears to persist through to later-life, acting via influencing childhood cognitive function, educational attainment, and occupational class (Richards & Sacker, 2010). There is therefore a great deal of influence of the 'environment' on cognitive performance, despite an accepted heritable component of cognitive functions (Arden et al., 2015).[2]

Just as the development of cognitive functions is malleable through early life experience, the decline of cognitive functions during ageing is also not inevitable. The ageing brain is plastic to social, behavioural, and environmental influences on cognition (Baltes, Staudinger, & Lindenberger, 1999; Mattson, Chan, & Duan, 2002; Nooyens et al., 2008). Higher educational attainment has been shown to slow the rate of cognitive decline, regardless of cognitive ability measured in childhood (Richards, Shipley, Fuhrer, & Wadsworth, 2004). Longitudinal cohort studies have also shown that having emotionally supportive relationships and a greater degree of social network attachment may be protective against decline in fluid cognitive functions during ageing (Giles, Anstey, Walker, & Luszcz, 2012; Seeman, Lusignolo, Albert, & Berkman, 2001). Several observational and intervention studies have shown exercise training to protect against cognitive decline in older adults in a dose-response fashion (Kirk-Sanchez & McGough, 2014). A dose-response relationship has also been shown between the lifetime number of cigarettes smoked and declines in memory, processing speed, cognitive flexibility, and global cognition

[2] The degrees to which cognitive functions are heritable, and the existence of a unitary, linear, and heritable 'intelligence' are highly contested. In this debate, the term 'environment' would refer to anything arising or occurring outside of a person's body.

(Nooyens et al., 2008). Cognitively stimulating activities such as reading literature, playing games such as chess and word games, and participating in cultural activities were associated with less global cognitive decline in four longitudinal studies with 21 years of follow-up data (Mitchell et al., 2012). However, it is still important to note that performance on tests of cognitive abilities in childhood still does consistently predict later-life cognitive function and decline (Deary, Pattie, & Starr, 2013; Richards & Sacker, 2010; Richards et al., 2004). Given the wide inter-individual variability in cognitive ageing, the balance of experiential factors in addition to the levels of cognitive skill and cognitive reserve built up in earlier life likely interact in a complex fashion to determine the degree of cognitive ageing experienced by a given individual.

3.2 Literacy and ageing

Age differences in the component processes involved in reading comprehension (i.e. literacy) have been observed (Hannon & Daneman, 2009). A meta-analysis of 194 articles published between 1941 and 1996 concluded that normal ageing is associated with decline in processing and remembering of written prose text (Johnson, 2003). More specifically, the ability to remember new text information, to make inferences about new text information, to access prior knowledge in long-term memory, and to integrate prior knowledge with new text information were lower among adults aged 64 and over relative to those aged 18 to 25 years (Hannon & Daneman, 2009). These component factors together explained most of the variation in overall reading comprehension among the older group of adults (Hannon & Daneman, 2009). Notably, these component factors involved in literacy include both the active learning of new information and the accessing of prior knowledge, integrating a range of fluid and crystallised cognitive functions. Since reading comprehension is vital to health literacy, these results indicate that health literacy may decline with increasing age in a linked fashion with the process of reading comprehension and fluid cognitive abilities. However, any aspects of health literacy that can be isolated to solely involve crystallised cognitive functions, such as the simple retrieval of medical vocabulary or existing knowledge from past experiences with health care, would not be expected to decline with age.

3.3 Cognitive function and health literacy

A body of cross-sectional evidence demonstrates that health literacy is correlated with various cognitive functions, independently of sociodemographic factors (D. W.

Baker et al., 2008; Federman et al., 2009; Gazmararian et al., 1999; Kobayashi et al., 2015; Levinthal et al., 2008; Morrow et al., 2006; Murray et al., 2011; E. A. H. Wilson, Wolf, Curtis, & Makoul, 2010; Wolf et al., 2012). Cognitive skills are necessary to navigate, process, and comprehend health information, to apply health information in a personal context, to appraise symptoms and access health services, to have successful interactions with health care providers, and to make decisions for personal health. There is therefore a natural overlap between health literacy and cognitive functions, as they are used in concert to achieve everyday goal-based health management tasks (Wolf et al., 2012).

Most tests of functional health literacy conflate cognitive function with health literacy, as both are simultaneously measured. Recalling the definition of functional health literacy, this construct is inextricably linked with both fluid and crystallised cognitive functions. For example, the REALM is a vocabulary test that likely relies on verbal fluency and general knowledge gained through experiential familiarity with medical words. In contrast, the TOFHLA and NVS require reading comprehension, computational skills, and reasoning skills in processing and applying health information to hypothetical health-related situations. The TOFHLA asks the subject to fill in missing words from sentences taken from health-related materials, such as X-ray preparation instructions and a hospital consent form (Parker et al., 1995). This task requires some past familiarity with clinical situations. The NVS asks the subject to read an ice cream nutrition label and compute how many calories or grams of fat are in various serving sizes and to interpret the allergy information on the label and apply it to a hypothetical situations where they, as the consumer, have an allergy (Weiss et al., 2005). However, despite the links between cognitive function and health literacy, there is a learned component of both literacy and health literacy; both constructs display strong and independent associations with educational attainment, socioeconomic factors, and English language proficiency (Harding et al., 2012; Kutner et al., 2006; Paasche-Orlow et al., 2005). Perhaps a relevant question is which aspects of health literacy are attributable to cognitive function, and to what degree, and which are unique to literacy.

Some studies have examined the relationships between various measures of health literacy and cognitive function. The most comprehensive to date is the ‘Health Literacy and Cognitive Function among Older Adults’, or, the ‘LitCog’ study (Wolf et al., 2012). The LitCog study assessed the fluid cognitive functions of processing speed, working memory, inductive reasoning, long-term memory, and prospective memory, along with crystallised verbal fluency, in addition to administering the TOFHLA, REALM, and NVS to 884 adults aged 55 to 74 years recruited from medical centres in Chicago, USA. In the study, scores on all three health literacy tests were moderately-to-strongly correlated with each of these cognitive functions (Wolf et al., 2012). When reduced to a single measure using factor analysis, the fluid functions measured (i.e. all except verbal fluency) were more strongly correlated with performance on the TOFHLA and on the NVS than with performance on the REALM (r=0.76 for the TOFHLA; 0.73 for the NVS; 0.57 for the REALM). Verbal fluency was similarly correlated with performance on all three tests (r=0.77 for the TOHFLA; 0.74 for the NVS; 0.71 for the REALM). Moreover, when variables for the fluid and crystallised functions were included in regression models with standardised scores on each of the TOFHLA, REALM, and NVS as the independent variables predicting performance on everyday health tasks, over 70% of each health literacy-health task performance association was explained (Wolf et al., 2012). Thus, these cognitive functions are correlated with health literacy, and, in this crude mediation analysis, explained a substantial proportion of the effect of health literacy on health tasks. This analysis was cross-sectional and used constructs that are inherently conflated with one another. However, each of the three health literacy tests still showed predictive capability for performance on health tasks that was independent of comprehensive cognitive function measures. In all, the ‘LitCog’ study indicates that health literacy and cognitive function have overlapping, but partly separate roles in predicting health management performance.

A Scottish longitudinal cohort study, the Lothian Birth Cohort 1936, has data on cognitive ability at age 11 (assessed with the Moray House Test No. 12; validated against a version of the Binet-Simon intelligence test scale) and follow-up data on cognitive ability at age 70 and health literacy at age 72 (Deary et al., 2007; Murray et al., 2011). The REALM, S-TOFHLA, and NVS were administered to 304 study participants at the age of 72. Moray House Test No. 12 score at age 11 was positively associated with health literacy score at age 76 for all three tests (adjusted β=0.61 for the S-TOFHLA, 0.40 for the REALM, 0.34 for the NVS; all $p<0.01$); relative change in intelligence test score from age 11 to 71 was positively associated with S-TOFHLA and NVS scores (adjusted β=0.44 for the S-TOFHLA and 0.16 for the NVS; both $p<0.04$); and the number of years of education was positively associated with NVS score (adjusted β=0.22; $p<0.01$) (Murray et al., 2011). Models were adjusted for sex, years of education, socioeconomic status, and the ‘big five’ personality traits of agreeableness, conscientiousness, extraversion, neuroticism, and openness (Murray et al., 2011). The association between IQ change and performance on the S-TOFHLA and NVS, but not REALM, is consistent with the postulation that REALM scores would be relatively stable with age as the performance on the test is related to crystallised abilities. These findings provide longitudinal evidence for the hypothesis that health literacy skills are a marker of underlying intelligence (Reeve & Basalik, 2014). However, this study also shows that education positively influences health literacy; therefore health literacy cannot be redundant against cognitive ability or intelligence, especially if the latter are viewed as inherent and heritable traits.

3.3.1 Age, cognitive function, and health literacy

A handful of other cross-sectional studies have investigated whether cognitive function plays a role in the association between age and health literacy in older adults. Two studies of older patients with heart failure (Morrow et al., 2006) and hypertension (Levinthal et al., 2008) found an association between increasing age and lower S-TOFHLA score, which was reduced to non-statistical significance by adjustment for verbal working memory, processing speed, visual function, and auditory function. In contrast, in two clinical samples of older adults (Armistead-Jehle, Cifu, Wetzel, Carne, & Klanchar, 2010; Chew, Bradley, Flum, Cornia, & Koepsell, 2004) and one sample of Medicare enrolees over age 65 (Gazmararian et al., 1999), the inverse association between age and TOFHLA score was maintained after adjusting for cognitive impairment according to the Mini-Mental Status Examination (MMSE). In other words, the correlation between increasing age and poorer TOFHLA performance was not explained by cognitive impairment in these three studies.

In a recent analysis of the LitCog study that I performed in early 2015, each of the fluid cognitive functions of processing speed, short-term memory, inductive reasoning, prospective memory, and long-term memory mediated the inverse relationship between age and TOFHLA score to some degree (Kobayashi et al., 2015). Processing speed was by far the strongest mediator of the age-TOFHLA score relationship; prospective memory and long-term memory minimally contributed to the relationship. On the other hand, no one single cognitive function mediated the inverse relationship between age and NVS score, but the incremental contributions of individual cognitive functions led to an overall mediating effect of fluid cognitive function on the age-NVS score relationship (Kobayashi et al., 2015). In that study, REALM score was not associated with age.

Health literacy, as assessed using an instrument similar to the TOHFLA, has also been strongly associated with the frequency of participation in cognitively stimulating activities such as newspaper reading and playing chess in a cross-sectional analysis of 556 non-demented older adults with a mean age of 83 years (J. S. Bennett, Boyle, James, & Bennett, 2012). However, due to the cross-sectional design of that analysis, it is difficult to tell whether engagement in cognitively stimulating activities helps to improve health literacy, or whether people with good health literacy more often engage in these types of activities from the outset.

3.4 Summary

Cognitive function tends to decline with age in a non-pathological manner (i.e. cognitive ageing), although the onset and rates of decline differ for differing aspects of cognitive function. Cognitive ageing is also not inevitable, and appears to be influenced by a range of intellectually stimulating activities. General literacy and health literacy skills have been observed to be lower in older adults than in younger adults, indicating that cognitive ageing may negatively affect literacy and health literacy skills. Furthermore, several cross-sectional studies have shown that functional health literacy is closely related to measures of cognitive function. The common functional health literacy tests (e.g. the TOFHLA, REALM, and NVS) appear to simultaneously assess both literacy and cognitive function, so there seems to be substantial overlap between the two constructs.

The conflation between health literacy and cognitive ability has provided fertile ground for cognitive epidemiologists to argue that health literacy is a simple proxy for intelligence, and therefore a concept of scientific redundancy that should not be investigated (Mõttus et al., 2014; Reeve & Basalik, 2014). This perspective ignores the socially constructed conceptualisation and measurement of both intelligence and health literacy, and it reifies a heritable unitary intelligence to be the salient predictor of health outcomes, upon which there is little room for intervention. This thesis takes the perspective that while cognitive function appears to influence performance on tests of health literacy, the idea that health literacy is entirely reflective of an entirely heritable and unitary intelligence is unlikely. There is a learned component to health literacy, evidenced by the independent effect of education on later-life health literacy (Gazmararian et al., 1999; Murray et al., 2011; Rowlands et al., 2013; von Wagner et al., 2007). Independently of cognitive function measures, health literacy predicts outcomes including health self-management, decline in physical function, and risk of all-cause mortality in older adults (D. W. Baker et al., 2008; Bostock & Steptoe, 2012; Murray et al., 2011; S. G. Smith et al., 2015a; Sudore et al., 2006; Wolf et al., 2012).

Given previous evidence showing that cognitive functions decline during ageing and that cognitive function and health literacy are cross-sectionally associated, I postulate in this thesis that health literacy skills decline with age in a manner that may be similar to cognitive ageing. Cognitive ageing would explain the consistent negative association between age and health literacy in cross-sectional studies. The specific health literacy skills that decline with age may map onto specific cognitive functions. However, health literacy is not assumed to necessarily decline with age, just as cognitive ageing is not inevitable. The cognitively stimulating technological and social engagement factors that have been shown to protect against cognitive ageing may also help to protect against ageing-related health literacy decline, if it is shown to occur in older adults. These associations are unknown, and have never been investigated longitudinally.

Chapter 4. Health behavioural outcomes of low health literacy

Understanding the potential ageing-related changes to health literacy is important if low health literacy in older age is consequential for health-related outcomes. Ageing is associated with many substantial life changes, such as increased risks for chronic illnesses and declines in cognitive and physical function, as well as social and economic changes due to retirement and changes in health and lifestyle (Batty et al., 2014; Steptoe, Deaton, & Stone, 2015; Steptoe, Shankar, Demakakos, & Wardle, 2013b; Thomas, 2011b). In older adults, health literacy has been shown to play an independent role, over and above poor cognitive function and other ageing-related factors, in predicting health outcomes including poor self-rated health, poor management of chronic disease, poor quality of life, incorrect taking of prescription medications, decline in physical function, and increased risk of all-cause mortality (D. W. Baker et al., 2008; Berkman et al., 2011; Bostock & Steptoe, 2012; Davis et al., 2006; S. G. Smith et al., 2015a; Sudore et al., 2006; M. Williams et al., 1998). Although the relationships between health literacy and outcomes related to the management of ill health have been frequently investigated, less is understood about the relationships between health literacy and habitual health-promoting behaviours in older adults (Berkman et al., 2011; von Wagner et al., 2009a). This chapter will review and present a theoretical framework for the role of health literacy in health-promoting behaviours in older adults.

Informed by the theoretical models of health literacy and health outcomes (Paasche-Orlow & Wolf, 2007) and health literacy and health actions (von Wagner et al., 2009a), which were introduced in Chapter 1, the latter empirical studies of this thesis will focus on the relationships between low health literacy and health behaviours in older English adults. ‘Health behaviours’ are defined as the habitual lifestyle behaviours that are consistently associated with risks of chronic disease and mortality among adults of all ages, these include moderate-to-vigorous intensity physical activity (MVPA), fruit and vegetable intake, alcohol consumption, and cigarette smoking (Bagnardi et al., 2014; Ford, Zhao, Tsai, & Li, 2011; Friedenreich & Orenstein, 2002; Hamer, de Oliveira, & Demakakos, 2014a; Khaw et al., 2008; Kvaavik, Batty, Ursin, Huxley, & Gale, 2011; Leitzmann et al., 2007; Ness & Powles, 1997; Rosenkranz, Duncan, Rosenkranz, & Kolt, 2013; Södergren, McNaughton, Salmon, Ball, & Crawford, 2012). Cancer screening will also be considered in this thesis as a ‘health behaviour’, due to the importance of screening for improved health outcomes in older adults, and the specific necessity of health literacy skills for decision-making about cancer screening (Davis, Williams, Marin, Parker, & Glass, 2002; Mandel et al., 1993; Mandel, Church, Ederer, & Bond, 1999).

4.1 Theoretical framework of health literacy and health behaviours

The theoretical models of health literacy and health outcomes and health actions, which were reviewed in Chapter 1, inform the latter studies of this thesis on health literacy and health behaviours in older adults. Paasche-Orlow and Wolf's original theoretical model (2007) postulates that health literacy affects health outcomes through influencing three domains of health actions: access and utilisation of health care, patient-provider interaction, and patient self-care (refer back to Figure 1.2, on page 20 in Chapter 1). In the 'patient self-care' domain lie the factors potentially relevant to health behaviours: knowledge/skills, problem solving, motivation, and self-efficacy (Paasche-Orlow & Wolf, 2007). This domain of the model, which primarily focuses on the self-management of chronic illness, emphasises that people with limited health literacy have lower knowledge about specific disease conditions than those with adequate health literacy. Examples may include what medication to take during an asthma exacerbation (among asthmatics), the symptoms of low blood sugar (among diabetics), and what blood pressure test result constitutes a high blood pressure (among hypertensive adults) (Paasche-Orlow & Wolf, 2007; M. Williams et al., 1998). In the model, health literacy is thought to directly enable a person to learn and gain knowledge about how to self-manage their health. However, the authors emphasise that health literacy alone is not sufficient to directly stimulate behaviour, and therefore include self-efficacy, defined as 'judgements of how well one can execute courses of action required to deal with prospective situations' (Bandura, 1977), as a key mediator lying on the causal pathway between health literacy and health outcomes.

The second model, of health literacy and health actions, elaborates upon the specific pathways between health literacy and the three domains of health actions from Paasche-Orlow and Wolf's original model (refer back to Figure 1.3, on page 21 in Chapter 1) (von Wagner et al., 2009a). The terms 'health behaviour' and 'health action' are used interchangeably in this model. Focusing again on 'patient self-care', this domain was renamed to 'management of health and illness' and expanded to include health-promoting lifestyle behaviours and habitual self-care health actions that contain an element of autonomy (von Wagner et al., 2009a). As briefly reviewed in Chapter 1, the model draws from the field of health psychology in theorising that health literacy influences health-promoting lifestyle behaviours through influencing the ‘motivational’ phase of behaviour (including knowledge, understanding, beliefs, and attitudes about a health action) and the ‘volitional’ phase of behaviour (the skills required to implement an action). In accordance with this theoretical model of health literacy and health actions, the role of health literacy within each phase of behaviour is discussed below.

4.1.1.1 Motivational phase of health behaviour

The motivational phase of behaviour consists of the psychological processes that ultimately influence a person’s decision to engage in a specific health behaviour, such as taking up physical activity or attending cancer screening. In the classic social cognitive models of health actions, such as the health belief model (HBM) or the theory of planned behaviour (TPB), a range of factors determine a person’s intention to engage (or not) in a behaviour (Ajzen, 1991; Armitage & Conner, 2000; Janz & Becker, 1984). These factors include perceived susceptibility to the health outcome that the action is intended to help a person avoid, the perceived severity of the health outcome, the perceived benefits of the health action, and the perceived barriers to engaging in the health action (all from the HBM), as well as self-efficacy to engage in the health action (from the TPB) (Ajzen, 1991; Janz & Becker, 1984).

von Wagner et al.’s model of health literacy and health actions posits that health literacy influences the motivational phase of health behaviour through influencing knowledge and attitudes (von Wagner et al., 2009a). Health literacy would affect whether a person takes notice of, seeks out, and engages with health information, which would in turn affect his or her knowledge and attitudes about the health issue in question (Boxell et al., 2012; Kobayashi & Smith, 2015; Koo, Krass, & Aslani, 2006; Morris et al., 2013; von Wagner, Semmler, Good, & Wardle, 2009b). For example, this would apply to decision-making about cancer screening (reading informational leaflets and understanding the purpose of screening), food and diet (reading nutritional labels when food shopping and researching healthy dietary options), physical activity (reading and learning about different types of exercise and sports, understanding the relation between exercise and health, appraising different types of exercise), and alcohol consumption (understanding alcohol unit sizes in relation to consumption guidelines and the negative consequences of heavy drinking). More generally, health literacy may also influence the passive learning about health issues that takes place during incidental exposure to health information that mostly occurs through various forms of media such as television, radio, newspapers, or the Internet (Kelly et al., 2010; Niederdeppe et al., 2007; Shim, Kelly, & Hornik, 2006).

There is some empirical support for the role of health literacy in the motivational phase of health behaviour: S-TOFHLA-assessed health literacy has been found to explain a small proportion of physical activity behaviour in a structural equation model, with paths from health literacy to knowledge about physical activity (r=0.22; p<0.001), knowledge to self-efficacy to engage in physical activity (r=0.13; p<0.01), and self-efficacy to frequency of physical activity over the past four weeks (r=0.17; p<0.01) (Osborn, Paasche-Orlow, Bailey, & Wolf, 2011). A similar result was found in a Dutch study on the mediating role of self-efficacy in the relationship between health literacy and physical activity (Geboers, Winter, Luten, Jansen, & Reijneveld, 2014). Self-efficacy has also been found to partly mediate the influence of health literacy in blood sugar control among diabetic adults (Osborn, Cavanaugh, Wallston, & Rothman, 2010). Low self-efficacy to complete a home-based colorectal cancer screening test (the faecal occult blood test, or FOBt) has also been associated with low health literacy in older English adults (von Wagner et al., 2009b).

4.1.1.2 Volitional phase of health behaviour

The volitional phase of behaviour follows the motivational phase of behaviour. It includes the action control or implementation strategies and skills that are used to translate intention into behaviour (Armitage & Conner, 2000). This phase of behaviour has also been called ‘behavioural control’ or ‘action control’ (Ajzen, 1991). Health literacy is postulated to directly influence the action control or implementation skills that are required to carry out behaviour, including planning, organising, and task-specific skills (von Wagner et al., 2009a). For example, having high health literacy would enable one to plan an appropriate exercise regime to achieve weight loss or fitness goals, to schedule and prepare for a cancer screening test appointment, or to seek out the necessary support and develop a strategy to quit smoking (von Wagner et al., 2009a). Despite the established theoretical importance of health literacy for health behaviour, empirical evidence for the role of health literacy in the volitional phase of behaviour is sparse. Comprehension and knowledge have been considered to be important volitional variables with relevance to the planning of behaviour as well as the motivation for behaviour. Adults with low health literacy have been found to frequently misunderstand prescription medication labels and subsequently take medication incorrectly (Davis et al., 2006). Older adults with low health literacy have also been found to experience a greater burden of information processing when reading the instructions for completing a cancer screening test than older adults with adequate health literacy (von Wagner et al., 2009b).

More broadly, evidence on the overarching relationships between health literacy and individual health behaviours is conflicting. Previous studies have examined the relationships between health literacy and health-promoting behaviours including physical activity, fruit and vegetable consumption, smoking, alcohol intake, seatbelt use, vaccination uptake, and cancer screening uptake, with inconsistent results (I. M. Bennett et al., 2009; J. S. Bennett et al., 2012; Geboers et al., 2014; Miller et al., 2007; Osborn et al., 2011; von Wagner et al., 2007; Wolf, Gazmararian, & Baker, 2007). These existing studies included adults of varying age ranges and they used differing health literacy tests (although, mostly the TOFHLA and the REALM) and different types of self-report measures of health behaviours, which may at least partly explain the inconsistent associations that were observed. All existing studies were cross-sectional in nature and failed to adjust for cognitive or physical health, which are major limitations of behavioural studies of health literacy. Chapter 11, which will examine the roles of health literacy and health literacy decline in the long-term maintenance of several health behaviours over time during ageing, will review in more depth the existing empirical evidence on health literacy and health behaviours in older adults.

4.2 Health behaviours in the context of ageing

The framework reviewed in this chapter is intended to apply to adults of all age ranges; it does not explicitly discuss the sociodemographic profile of adults that it is meant to cover. The motivational and volitional processes underlying health behaviour are probably similar across all age groups, as there is little theory or evidence to the contrary. However, Paasche-Orlow and Wolf note that limited health literacy is increasingly prevalent with older age, and also that ageing-related factors need to be disentangled from limited health literacy in the causation of health outcomes (Paasche-Orlow & Wolf, 2007). Older adults experience additional personal and external barriers to engagement in health-promoting behaviour that younger adults would less often encounter. For example, the ageing-related declines in cognitive and physical function that older adults often face would inhibit engagement in several health behaviours, such as cancer screening and physical exercise (Gale, Deary, Wardle, Zaninotto, & Batty, 2015; Matthews, Demakakos, Nazroo, & Shankar, 2014; L. Smith, Gardner, Fisher, & Hamer, 2015). Changing life circumstances as one ages, such as experiences of social isolation, lack of transport, or declining income could also inhibit engagement in health behaviours (Matthews et al., 2014; Thomas, 2011b). These barriers could override any effect of health literacy on health behaviour, as they would negate any effect of knowledge or motivation to affect behaviour.

4.3 The contextual aspects of health literacy

Despite the individualistic frameworks of health literacy presented in Section 4.1, it is important to remember that the style and content of health information and the way in which it is communicated also determines whether a person's health literacy is adequate to use the information. Furthermore, the health needs of a person also determine what types and levels of health literacy skills are important for him or her. For example, a person who is diagnosed with cancer and needs to make several decisions about their treatment and care has different immediate health literacy needs than a person whose most pressing health concern is shopping for their family's weekly groceries on a limited budget. Note that a person at different time points in his or her life may encounter each of these circumstances. In this way, health literacy is contextual. Figure 4.1 illustrates how health literacy is at once personal and contextual. Unfortunately, most current assessment tools for health literacy do not account for people's specific requirements for health literacy skills based on their personal circumstances or the health information environments in which they live. However, regardless of this contextual nature of health literacy, low scores on the TOHFLA, NVS, and REALM are consistently associated with poor behaviours relating to the management of illness in adults of all age ranges, including higher rates of hospitalization, poor knowledge of disease management among people with specific chronic diseases, and incorrect taking of prescription medications (Berkman et al., 2011).

Figure 4.1 Interactive framework of health literacy

4.4 Summary

Low health literacy has been robustly associated with several health-related outcomes in older adults, including poor knowledge about the management of illness, incorrect taking of prescription medications, decline in physical function, poor self-rated health, poor quality of life, and risk of all-cause mortality (D. W. Baker et al., 2008; I. M. Bennett et al., 2009; Berkman et al., 2011; Bostock & Steptoe, 2012; Davis et al., 2006; S. G. Smith et al., 2015a; Sudore et al., 2006; M. Williams et al., 1998). In contrast, the relationships between health literacy and health-promoting behaviours have rarely been investigated. Health-promoting behaviours include lifestyle behaviours that are consistently and robustly associated with risks of chronic illness and all-cause mortality in older adults, including moderate-to-vigorous intensity physical activity, fruit and vegetable intake, alcohol consumption, smoking, and cancer screening (Bagnardi et al., 2014; Ford et al., 2011; Friedenreich & Orenstein, 2002; Hamer et al., 2014a; Khaw et al., 2008; Kvaavik et al., 2011; Leitzmann et al., 2007; Mandel et al., 1993, 1999; Rosenkranz et al., 2013; Södergren et al., 2012). A theoretical framework of health literacy and health outcomes and actions can inform inquiry into the relationships between health literacy and health behaviour. Drawing from health psychology theory, health literacy is thought to influence both the motivational and volitional phases of behaviour. Specifically, health literacy is thought to influence a person's access to and use of relevant information to gain knowledge and in turn develop their motivation and self-efficacy to engage in behaviour, and also influence the planning and implementation of behaviour. The role of health literacy in determining health behaviours among older adults is not well understood.

While health literacy is conceptualised as an attribute of individuals in the theoretical frameworks underlying this thesis, it is important to remember that the types and complexity of information accessible to an individual determines whether his or her health literacy is adequate. Further, health literacy skills are contextual in that different types of skills may be relevant to different people in different situations, and people's requirements for health literacy may change throughout their lives. Most current health literacy assessment tests do not account for this contextual aspect of health literacy. Given that health literacy is an issue of health equity, as not all health information is available or accessible to everyone in society, it may in part contribute to social inequalities in health promoting lifestyle behaviours and, in turn, health outcomes in later life (Rowlands et al., 2015; Shaw, McGeever, Vasquez, Agahi, &

Fors, 2014). Understanding the relationships between health literacy and health-promoting lifestyle behaviours in older adults will be important to identify areas where health education and communication strategies may be improved to better enable the older public to maintain health and well-being during ageing.

Chapter 5. Aims of the thesis

A body of cross-sectional evidence indicates that older adults have lower health literacy than younger adults, although no longitudinal, within-person evidence for this relationship exists. Therefore, the following are unknown: whether health literacy declines with increasing age; the age(s) at which older adults may begin to lose health literacy skills; the epidemiology of health literacy decline during ageing; the roles of cognitive function and cognitive decline in performance on health literacy tests and in decline over time in health literacy test performance; the relationships between Internet use, social engagement and health literacy decline; and, the long-term health behavioural outcomes of low and declining health literacy. Using rich longitudinal data to track health literacy over time among older English adults, this thesis will improve upon previous cross-sectional research and add new knowledge to the ageing and health literacy research fields.

Specifically, this thesis aims to address the following research questions:

1. What is the association between age and health literacy in older adults, overall and according to different health literacy tests?

2. Does health literacy decline during ageing, and, if so, at what age(s) might older adults become vulnerable to decline in health literacy?

3. What are the sociodemographic risk factors for ageing-related health literacy decline?

4. What are the roles of cognitive function and cognitive decline in ageing-related health literacy decline?

5. Could Internet use and social engagement (known protective factors against cognitive decline) protect against health literacy decline during ageing?

6. Are health literacy and ageing-related health literacy decline related to participation in colorectal cancer screening through the organised national cancer screening programme in England?

7. Are health literacy and ageing-related health literacy decline associated with long-term engagement in health-promoting behaviours (weekly moderate-to-vigorous physical activity, five-daily fruit and vegetable intake, non-problematic drinking, and non-smoking) during ageing?

These research questions are addressed in a series of five empirical studies. The first study is a systematic review and meta-analysis of existing cross-sectional literature on the association between age and health literacy, according to various health literacy tests that assess differing components of functional health literacy skills (Research Question 1). Studies 2 through 5 then use data from the English Longitudinal Study of Ageing. Studies 2 and 3 both focus on longitudinal changes to health literacy (i.e. health literacy decline) during ageing. Study 2 is an epidemiological analysis of health literacy decline during ageing that investigates whether health literacy declines over time during ageing, the age(s) at which health literacy may begin to decline (RQ 2), the sociodemographic risk factors for ageing-related health literacy decline (RQ 3), and, the potential roles of cognitive function and decline as predictors of ageing-related health literacy decline (RQ 4). Study 3 investigates the modifiable behavioural predictors of health literacy decline that are known to be associated with cognitive ageing: Internet use and social engagement in the domains of civic activities, leisure activities, and cultural activities (RQ 5). These first three studies contribute to the ageing and health literacy literatures by systematically reviewing the existing cross-sectional evidence and then using longitudinal data to characterise health literacy decline during ageing and its sociodemographic, cognitive, and behavioural predictors in older English adults.

Then, Studies 4 and 5 move onto the health behavioural outcomes of low health literacy and ageing-related health literacy decline. Study 4 examines the relationships between a) low health literacy, b) ageing-related health literacy decline, and the uptake of colorectal cancer screening in England’s national screening programme (RQ 6). Study 5 examines the relationships between a) low health literacy, b) ageing-related health literacy decline, and the long-term maintenance of each of leisure-time moderate-to-vigorous physical activity, five daily servings of fruit and vegetables, non-problematic alcohol consumption, and non-smoking over an eight-year period during ageing (RQ 7). Important control variables in both studies are cognitive function and ageing-related cognitive decline, as well as other social, socioeconomic, and health-related factors that might inhibit an older person’s capacity to engage in health-promoting behaviour. These two final studies contribute to the literature by using longitudinal data to give an indication as to whether health literacy has a role in predicting health behaviours in older adults, independently of ageing-related social, socioeconomic, cognitive, and health-related factors.

5.1 My contributions to the research in this thesis

I developed the aims of thesis and designed the five studies with input from my supervisors Professor Jane Wardle and Dr Christian von Wagner. I performed all of the statistical analysis, and interpreted the results with input from my supervisors. I wrote the thesis, which I received feedback on from my supervisors prior to submission. My collaborator Professor Michael Wolf at the Feinberg School of Medicine at Northwestern University contributed to the interpretation of results and revision of the published peer-reviewed manuscripts that correspond to Studies 1 and 2, and the results for physical activity in Study 5. He has not seen the thesis and did not contribute directly to the thesis.

I obtained statistical advice on the appropriateness of effect size measures vs. odds ratios as the output statistics for the meta-analysis in Study 1 from a colleague at the Health Behaviour Research Centre, Dr Benjamin Gardner. I played no role in the design or data collection of the English Longitudinal Study of Ageing; this study had been on-going for nearly ten years at the time when I began my PhD. I accessed and downloaded the publicly available ELSA data from the UK Economic and Social Data Service website. I am responsible for all management and analysis of ELSA data in this thesis. The only exception is for the net non-pension wealth quintile variable, which was calculated by Professor Andrew Steptoe.

Chapter 6. Study 1: Ageing and health literacy: a systematic review and meta-analysis[3]

6.1 Background

As reviewed in the introductory chapters to this thesis, an inverse relationship between age and performance on tests of health literacy is apparent. However, the body of literature on this relationship has never been synthesized in a meaningful way, which would be useful prior to a longitudinal examination. In older adults, health literacy skills are related to several different aspects of cognitive function (Federman et al., 2009; Reeve & Basalik, 2014; Wolf et al., 2012). Fluid cognitive functions such as verbal fluency, working memory, and reasoning are important for performance on health literacy tests, and they undergo mild decline during ageing in the absence of dementia as early as mid-adulthood, whereas crystallised cognitive functions such as generalised knowledge and vocabulary are more stable with age (Deary et al., 2009; O'Carroll, 1995; Singh-Manoux et al., 2012). Therefore, performance on health literacy tests that are similar to tests of fluid cognitive function, such as the TOFHLA and NVS may decline with age (Parker et al., 1995; Weiss et al., 2005). In contrast, performance on tests that assess health literacy as medical vocabulary, such as the REALM, may show little decline with age (Davis et al., 1993).

If health literacy skills represent the functional use of cognition in health contexts, then certain health literacy skills, but not others, would be expected to decline with age. Furthermore, cognitive ageing would at least partly explain a potential inverse association between age and health literacy. The aim of the systematic review and meta-analysis presented in this chapter was therefore to synthesise the existing evidence on the association between age and health literacy, overall and by health literacy test, and to investigate the mediating role of cognitive function in this relationship. I hypothesised that functional health literacy, as assessed by the TOFHLA, NVS, and similar tests (representing fluid cognitive functions) would be more likely to show an inverse association with age than health literacy as assessed by the REALM and similar tests (representing crystallised cognitive functions); and that cognitive function would at least partially mediate any relationship between age and TOFHLA-assessed or NVS-assessed health literacy score.

[3] A version of this Chapter has been published in *J Gerontol B Psychol Sci Soc Sci* (Appendix 7.1)

6.2 Methods

6.2.1 Identification of studies

This systematic review and meta-analysis was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement recommendations (Moher, Liberati, Tetzlaff, & Altman, 2009). I developed the search strategy jointly with Dr von Wagner, following instruction from University College London librarians. I searched the Embase, MEDLINE, and PsycINFO databases for relevant articles conducted in any country or language and published in English through September 30, 2013 (see Appendix 7.2 for the complete electronic search strategy). I included studies in a narrative synthesis if health literacy was measured using an objective instrument (the TOFHLA, REALM, or NVS; see Table 6.1), and if a measure of association between age and health literacy was presented with an associated statistical significance level. I excluded studies where the study population did not include adults aged ≥50 years or if the study population was entirely comprised of individuals with diagnosed cognitive or mental health impairments, as they would be restricted in the variance of cognitive function among participants. Studies were included in the meta-analysis if odds ratios (OR) and 95% confidence intervals (CI) for limited health literacy by age were computable from the presented results (≥65 vs. <65 years; if this comparison was not available, then similar cut-offs were acceptable).

Table 6.1 Characteristics of the Health Literacy (HL) Tests: the 'Test of Functional Health Literacy in Adults' (TOFHLA), the 'Newest Vital Sign' (NVS), and the 'Rapid Assessment of Literacy in Medicine' (REALM)

Test	Measure	Skills assessed	Scoring	Adaptations
TOFHLA (1995)	Common medical materials (e.g. prescription labels) followed by comprehension questions using the Cloze procedure – a technique that omits every 5-7 words in a sentence 22 minutes to administer	Reading comprehension (50 items) Numeracy (17 items)	0-59: Inadequate HL 60-74: Marginal HL 75-100: Adequate HL <75: Limited HL	UK-TOFHLA Translations: Korean, Serbian, French, Italian, German, Portuguese Short form: S-TOFHLA
NVS (2005)	A 6-item test based on the ability to read and apply information from an ice cream nutrition label 3 minutes to administer	Reading comprehension Numeracy	<2: Greater than a 50% chance of having marginal or inadequate HL 2-4: Possibility of limited HL >4: Adequate HL	Translation: Turkish
REALM (1991)	66 medical words ranging from 'fat', 'flu' and 'pill' to 'obesity', 'osteoporosis', and 'impetigo', which the subject is instructed to read out loud 2-3 minutes to administer	Word recognition Pronunciation	Reading level according to score: 0-18: $\leq 3^{rd}$ grade 19-44: 4-6^{th} grade 45-60: 7-8^{th} grade 61-66: $\geq 9^{th}$ grade <61: Limited HL	Translation: Turkish Short forms: REALM-R, REALM-SF

6.2.2 Article screening and data abstraction

I screened the returned article titles and abstracts, and downloaded those that did not meet the exclusion criteria in full text. I screened the methods and results sections of the downloaded articles for final inclusion. When multiple articles on the same study population were eligible, either the article that was published first or the one that presented a multivariable-adjusted measure of association was selected. I hand-searched reference lists of included articles for additional references. I performed the initial search, screening, and data extraction, and Dr von Wagner checked all included articles and extracted data. We were in 100% agreement over the articles included and data extracted. The data items extracted were: (a) study design, country, and language of conduct, source of the study population, inclusion and exclusion criteria, sample size, and participation rates; (b) age statistics of the study population, including mean, median, and range; (c) the health literacy instrument used and health literacy score/level of the study population by age in categories defined by the study authors, if given; and (d) the measure of association between health literacy and age with corresponding p-values, the statistical test(s) used, and confounding variables adjusted for, including cognitive function (if applicable). I followed the recommendations in the Cochrane handbook to develop risk criteria based on existing guidelines (The Cochrane Collaboration, 2011; von Elm et al., 2007; Wells et al., n.d.): (a) study designs – with prospective studies ranked as having lower risk of bias; (b) participation rate – those with higher participation rates ranked as having lower risk of bias; and (c) adjustment for confounding. All eligible analyses were cross-sectional and only half reported participation rates; I therefore categorized risk of bias according to the third criterion only.

6.2.3 Statistical analysis

As a scoping summary to aid the narrative review, the percentage of studies detecting a statistically significant association between age and health literacy was calculated for all studies combined by health literacy test, by participation rate, and by whether they reported an adjusted measure of association. For the meta-analysis, the outcome was a pooled OR and 95% CI for the association between age and limited health literacy. The age cut-off of 65 years was chosen, as it is useful in terms of policy purposes (e.g., it is the age of retirement in several Western countries) and because it was a common cut-off used in studies in an early literature scan. “Limited” health literacy was the outcome (Table 6.1). Limited health literacy represents a clinically significant cut point where individuals begin to have difficulty with everyday health tasks and where the risks of several adverse health outcomes begin to increase (Davis et al., 2006; S.-Y. D. Lee et al., 2009; Peterson, Dwyer, Mulvaney, Dietrich, & Rothman, 2007; Scott, Gazmararian, Williams, & Baker, 2002; Sudore et al., 2006).

Standardized effect size measures (e.g., Cohen’s d or Hedge’s g) were not used for this analysis. Meta-analytic techniques pooling these measures would assume that between-study variations in the standard deviations for mean health literacy scores are due to scale differences, rather than to any true variability in health literacy test performance between study populations (Greenland & O’Rourke, 2008; The Cochrane Collaboration, 2011). This assumption cannot be made in the context of my meta-analysis, given that the varying sociodemographic compositions of individual study populations including varying age ranges, countries, and languages would likely give rise to variability in health literacy performance between studies.

When effect estimates were not reported as ORs for limited health literacy, but data were sufficient to compute these values (i.e., in cross-tabular format), they were transformed into ORs using Comprehensive Meta-Analysis (CMA) software (Version 2.2.064). As raw ORs cannot be meaningfully aggregated, all ORs were transformed to the natural log (lnOR) for analyses, then transformed back to OR and 95% CI for interpretation. In cases where ORs for limited health literacy could not be computed, study authors were contacted to retrieve the data in an appropriate format for data synthesis. Studies reporting mean age by categories of health literacy score (n=20) were excluded from the meta-analysis as these studies treat age as the dependent variable and thus cannot produce an OR predicting health literacy. These studies were summarized narratively.

The meta-analysis was performed using fixed- and random-effects models. The random-effects model is likely to be more valid, as the true association between age and health literacy cannot be assumed equal between studies for the same reason that variability in health literacy performance across study populations must be assumed. Heterogeneity in the fixed-effects models was assessed using the Q value and Higgins and Thompson's I^2 statistics. The Q value tests whether the observed variance in effects is not greater than that would be generated by sampling error; a Q value with a corresponding $p<0.05$ indicates the presence of heterogeneity and that a random-effects model is appropriate. The I^2 statistic is an estimate of the proportion of total variation in study estimates due to heterogeneity (The Cochrane Collaboration, 2011). Fixed-effects models with corresponding heterogeneity tests were ran first, followed by random-effects models. The meta-analysis was performed for all studies together and stratified by health literacy test, to test my hypothesis that study results would differ by test.

A sensitivity analysis removing one study at a time from the pooled analysis examined for influential individual studies on the overall pooled result. This technique allows for identification of particular aspects of an individual study that may skew the overall combined result. A second sensitivity analysis was performed, removing from the meta-analysis all studies using age cut-offs other than age 65. A random-effects meta-regression was performed to assess the extent to which heterogeneity in the pooled result can be related to each of the following individual study characteristics: health literacy test, health status of study population, country of study, language of study, and participation rate. Publication bias was assessed using the classic fail-safe N method, which is the theoretical number of unpublished studies with a null result that would be required to render the calculated pooled result null. A funnel plot of standard error by lnOR was also generated, and Duval and Tweedie's "trim and fill" method used to estimate the number of studies missing due to publication bias. This method provides an imputed estimate of the pooled effect size after publication bias is taken into account (Greenland & O'Rourke, 2008). All statistical analyses were conducted using Comprehensive Meta-Analysis (Biostat, Englewood, NJ) and StataSE 13.1 (StataCorp, College Station, TX).

6.3 Results

6.3.1 Search results

A total of 70 analyses in 60 studies with data on 33,379 participants were included in the narrative review. A total of 29 analyses with data on 18,492 participants were included in the meta-analysis (Figure 6.1).

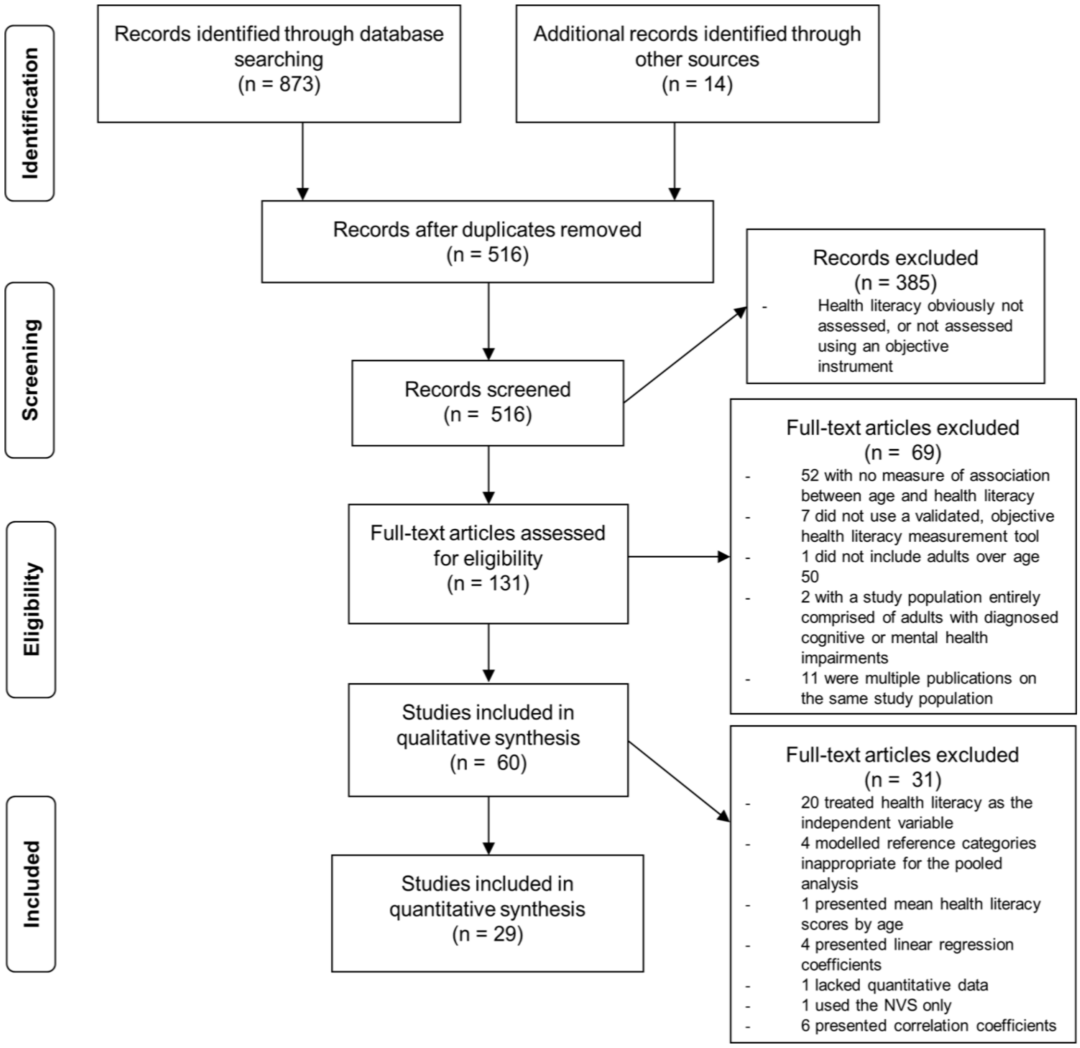

Figure 6.1 PRISMA flow diagram

6.3.2 Overview of included studies

6.3.2.1 Countries of origin

Studies were conducted in nine different countries and languages (Table 6.2). The predominant country of study was the United States and the predominant language English. All manuscripts were written in English.

Table 6.2 Characteristics of included studies, n=60

#	Reference	Country (language)	Sample composition	Age Statistics	Results for age and health literacy	Covariates adjusted for	p-value for difference
				STUDIES WITH A LOWER RISK OF BIAS			
				A) TOFHLA AND S-TOFHLA			
1	Armistead-Jehle et al., 2010	United States (English)	44 male patients referred to a movement disorders clinic in a Veteran's Affairs Medical Centre with no gross dementia (MMSE)	Mean: 69.7 SD: 8.4 Range: 55-88	Mean TOFHLA score: 81.6 Correlation coeff. between TOFHLA score and age: 0.48 Age was negatively associated with TOFHLA score: β=-0.24 (B=-0.74; SE_B=0.29)	Education, MMSE score (cognitive function), UPDRS (Unified Parkinson Disease Rating Scale) score, years with movement disorder, comorbidities	p<0.01 for correlation p<0.05 for β coefficient from multiple linear regression
2	Backes et al., 2012	United States (English)	79 adults from outpatient pharmacies	Inclusion: ≥18 Mean: 54 SD: 15	Mean (SD) age by S-TOFHLA score: Inadequate (n=27): 58 (13) Adequate (n=52): 52 (16) Effect estimate from logistic regression not given; older age was associated with inadequate HL	Education, sex, race	0.09 for inadequate vs. adequate HL groups <0.005 from logistic regression
3	Carthery-Goulart et al., 2009	Brazil (Portuguese)	312 healthy volunteers using hospital services with no cognitive or visual impairments, no untreated chronic conditions	Inclusion: ≥18 Mean: 47.3 SD: 16.8 Range: 19-81	Correlation coeff. for age and S-TOFHLA score: r=-0.259 Age did not predict S-TOFHLA score in multiple linear regression: B=-0.035, β=-0.22	Years of schooling	p<0.01 for bivariate correlation; p=0.584 for regression coefficient
4	Chew et al., 2004	United States (English)	332 patients with adequate vision and no severe dementia from a Veteran's Affairs preoperative clinic	Inclusion: >18 Mean: 58.2 SD: 13.1	N % with limited; adequate S-TOFHLA score: Ages <65(n=221): 12 (5%); 209 (95%) Ages ≥65 (n=111): 28 (25%); 83 (75%) Older age (≥65 years) associated with limited vs. adequate HL: OR=3.7 (95% CI: 1.7-8.1) Reference group: <65 years	Cognitive impairment, education less than high school, employment status	<0.001 for the proportions with limited HL by age (chi-square test) Not given for OR in logistic regression
5	Connor et al., 2013	Switzerland (German, Italian, and French)	659 Swiss residents recruited in random public places	German: Mean: 36 SD: 16.3 Italian: Mean: 47 SD: 20.1 French: Mean: 37 SD: 16.3	Mean (SD) S-TOFHLA score by age (German; Italian; French): Ages 18-45: 32 (3.2); 29 (6.2); 30 (6.1) Ages 45-65: 30 (5.4); 24 (8.5); 27 (9.8) Ages >65: 26 (9.7); 17 (8.9); 26 (7.1) Older age associated with lower HL: standardized betas were -0.288 (German), -0.459 (Italian), and -0.326 (French)	Education, chronic condition, gender	p-values for mean HL by age group: p<0.001 for German and Italian; p=0.042 for French (ANOVA); p<0.001 for linear regression betas
6	Gazmararian et al., 1999	United States (English and Spanish)	3,260 new Medicare enrolees from four Prudential HealthCare plans who had no visual or cognitive impairments and did not live in nursing	Inclusion: ≥65	N (%) with inadequate; marginal; adequate S-TOFHLA score: Ages 65-69: 188 (16%); 104 (9%); 913 (76%) Ages 70-74: 199 (22%); 96 (11%); 594 (67%) Ages 75-79: 170 (27%); 88 (14%); 370 (59%) Ages 80-84: 141 (39%); 56 (15%); 165 (46%)	Study location, race/language, sex, education completed, occupation, cognitive impairment (MMSE)	p<0.001 for proportions with inadequate or marginal HL by age (chi-square test)

			homes		Ages ≥85: 102 (58%); 22 (12%); 52 (30%) Older age associated with inadequate/marginal (vs. adequate) HL: OR (70-74) = 1.83 (95% CI: 1.43-2.33) OR (75-79) = 2.91 (95% CI: 2.23-3.81) OR (80-84) = 5.33 (95% CI: 3.89-7.31) OR (≥85) = 8.62 (95% CI: 5.55-13.38) Reference group: 65-69 years		Not given for OR from logistic regression but statistically significant
7	Ginde et al., 2008	United States (English and Spanish)	300 patients from 3 Boston emergency departments who spoke English or Spanish, had no altered mentation, no sexual assault, and no corrected visual acuity	Inclusion: ≥18 Mean: 42	N (%) with limited; adequate S-TOFHLA score: Ages 18-44 (n=148): 24 (16%); 124 (84%) Ages 45-64 (n=97): 32 (33%); 65 (67%) Ages ≥65 (n=53): 18 (34%); 35 (66%) Older age associated with limited (vs. adequate) HL: OR (45-64 years) = 4.3 (95% CI: 2.0-9.2) OR (≥65 years) = 3.4 (95% CI:1.4-8.51.4) Reference group: 18-44 years	Gender, ethnicity, race, first language, preferred language, education, income	p=0.003 for proportions with limited HL by age (chi-square test) Not given for OR from logistic regression but statistically significant
8	Jackson et al., 2007	United States (English)	99 adults from university-based health research panel	Mean: 71.0 SD: 5.9 Range: 59-85	Mean (SD) age by S-TOFHLA score: Inadequate (n=2): 80.0 (7.1) Marginal: (n=10): 74.2 (4.3) Adequate (n=86): 70.4 (5.8) Total score decreased with age in multiple linear regression (effect estimate not given)	Gender, ethnicity	p<0.01 for coefficient from multiple linear regression
9	Jovic-Vranes et al., 2009	Serbia (Serbian)	120 patients from an urban and a rural primary health care center	Inclusion: ≥18 Mean: 52.79 SD: 14.68 Range: 21-84	Mean (SD) TOFHLA score by age: Ages ≤44 (n=26): 87.19 (9.60) Ages 45-54 (n=22): 75.59 (18.78) Ages 55-64 (n=35): 70.60 (15.93) Ages ≥65 (n=22): 59.82 (16.53) Older age (per year) associated with marginal or adequate HL: OR=4.86 (95% CI: 2.41-9.80)	Education, having a chronic condition	p=0.000 for chi-square test (HL categories by age groups) p=0.000 for OR from logistic regression
10	Jovic-Vranes et al., 2011	Serbia (Serbian)	1,361 primary care patients	Inclusion: ≥18 Mean: 52.25 SD: 16.63 Range: 18-99	N (%) with inadequate; marginal; adequate S-TOFHLA score: Ages ≤44: 59 (14%); 40 (9%); 327 (77%) Ages 45-64: 158 (29%); 98 (18%); 296 (54%) Ages ≥65: 196 (56%); 51 (15%); 102 (29%) Younger age associated with adequate (vs. limited) HL: OR (≤44): 5.40 (95% CI: 3.10-9.58) OR (45-64): 2.32 (95% CI: 1.49-3.60) Reference group: ≥65 years	Gender, marital status, employment status, educational attainment, socioeconomic status, self-perceived health, number of chronic conditions	p=0.000 for distribution of HL score by age (chi square test) Not given for logistic regression
11	Jovic-Vranes et al., 2012	Serbia (Serbian)	824 female primary health care patients	Inclusion: ≥18 Mean: 51.64	Mean (SD) S-TOFHLA score by age: Ages ≤44 (n=263): 26.41 (8.1)	Employment status, education, material	p-value for distribution of mean

				SD: 16.42	Ages 45-64 (n=354): (9.0) Ages ≥65 (n=192): 16.29 (9.7) Younger age (≤44) associated with adequate (vs. limited) HL: OR = 2.42 (95% CI: 1.45-4.04) Reference group: >44	status, self-perceived health, chronic conditions	HL score across age groups not given but significant; p=0.001 for OR in logistic regression
12	Laramee et al., 2007	United States (English)	172 adults with diabetes in primary care, originally from the Vermont Diabetes Information System Field Survey study	Mean: 65 Range: 22-93	Older age (≥65 years) associated with limited (vs. adequate) S-TOFHLA score: OR = 3.51 (95% CI: 2.18-5.63) Reference group: <65 years	Sex, race, marital status, insurance, income, education, heart failure	p<0.001 for OR from logistic regression
13	Levinthal et al., 2008	United States (English)	492 community dwelling adults diagnosed with hypertension, primarily female (78%) and African American (68%)	Mean: 56.6 SD: 10.8 Range: 21-92	Correlation for age and S-TOFHLA score: r=-0.28 Older age (per year) associated with lower score: β=-0.05 with adjustment for sensory and cognitive function (model 3) Age explained 6% of variation in HL score; education explained 18%; cognitive variables explained 41%	Gender, race, comorbidities, systolic blood pressure, education, cognitive and sensory function	p<0.05 for bivariate correlation; p<0.10 for age in model
14	Morris et al., 2011	United States (English)	103 hospitalized patients assessed at discharge	Inclusion: ≥18 Mean: 64 SD: 16 Range: 23-92	Mean (SD) age by S-TOFHLA score: Inadequate: 70 (14) Marginal: 68 (10) Adequate: 56 (16) Older age (per year) less likely to have adequate HL: OR=0.93 (95% CI: 0.89-0.97)	Gender, education, income	p<0.001 for both bivariate measure of association and for OR from logistic regression
15	Morrow et al., 2006	United States (English)	314 community-dwelling adults diagnosed with chronic heart failure from an urban hospital	Mean: 62.9 SD: 8.5 Range: 47-89	Correlation coefficient for age and S-TOFHLA score: r=-0.11 Age not associated with HL in multivariable modelling: β=0.09	Gender, race, comorbidities, education, mental processing speed, speech comprehension, listening span, visual and auditory function	p<0.05 for bivariate correlation; Not given for β from regression, but not significant
16	Olives et al., 2011	United States (English and Spanish)	960 adults presenting to a suburban emergency department with no altered mental status, high acuity complaint, not in police custody, and not deemed to be 'vulnerable'	Inclusion: >18 Mean: 36.7 SD: 13.7	Increasing age (per year) associated with higher odds of inadequate: OR = 1.08 (95% CI: 1.05-1.10) and marginal: OR = 1.03 (95% CI: 1.00-1.05) vs. adequate	Sex, primary language, ethnicity, access to a primary care provider, years of education in the U.S., self-reported health, employment, housing, insurance, and chronic disease status	p<0.001 for inadequate HL and p=0.031 for marginal HL (from logistic regression)
17	Robinson et al., 2011	United States (English)	612 rural-dwelling adults with stable heart failure and no serious comorbidity affecting cognition	Inclusion: ≥18 Mean: 66.0 SD: 13.0	Age (continuous) was a negative predictor of S-TOFHLA score (continuous); the association was stronger with the 7 min test time limit (β=-0.740) than with no time limit (β=-0.317)	Gender, education, income	p<0.001 for both β coefficients

18	von Wagner et al., 2007	United Kingdom (English)	719 population-representative adults with no visual impairments identified through random location sampling	Inclusion: ≥18 Mean: 47.6 SD: 18.3 Range: 18-90	Mean (SD) age by UK-TOFHLA score: Inadequate (n=41): 63.9 (19.5) Marginal (n=41): 60.2 (20.9) Adequate (n=637): 45.2 (17.2) Older age associated with limited HL: OR (per year)=1.04 (95% CI: 1.02-1.06)	Gender, ethnic background, first language, educational attainment, annual personal income	p<0.0001 for logistic regression OR
					B) NVS		
19	Adams et al., 2009	Australia (English)	2824 adults in the South Australian Health Omnibus Survey	Not given	Proportions with limited NVS score by age: 15-24 years: 13% 25-44 years: 11% 45-64 years: 18% ≥65 years: 50% OR for limited vs. adequate score: OR=12.4 (6.6-23.2) for ≥65 vs. 15-24	Sex, residence area, education, income, cohabitation, birth region, general health status, private health insurance	OR from multiple logistic regression statistically significant
20	Shah et al., 2010	United States (English)	808 adults from 4 primary care centres	Mean: 44.9 SD: 15.0 Range: 18-91	Mean (SD) age by NVS score: Limited: 53.3 (15.2) Possible limited: 45.9 (15.4) Adequate: 40.0 (12.5) OR=0.95 (0.94-0.97) for adequate HL per year increase in age	Gender, race, education, BMI, having taken a health class	p<0.0005 for age I health literacy (ANOVA) OR statistically significant
					C) REALM and its short forms		
21	Rowlands et al., 2013	United Kingdom (English)	659 coronary heart disease patients from 16 general practices in South London	Inclusion: ≥18	Mean age (SD) by REALM score: <9th grade: 68.92 (11.84) ≥9th grade: 71.14 (10.14) OR=1.00 per year increase for <9th vs. ≥9th grade	Gender, ethnicity, index of multiple deprivation, education, employment, alcohol intake, BMI, depression and anxiety	p=0.049 for bivaria association; p=0.8 for OR from logisti regression
22	Sudore et al., 2006	United States (English)	2,512 community-dwelling, Medicare-eligible men and women with good physical functioning	Mean: 75.6 SD: 2.8 Range: 71-82	Mean (SD) age by REALM score: 0-6th grade (n=212): 75.8 (2.9) 7-8th grade (n=383): 75.7 (2.9) ≥9th grade (n=1,917): 75.6 (2.8) Older age not associated with limited HL: OR (≥77 years): 1.05 (95% CI: 0.84-1.31) Reference group: <77 years	Race, sex, income, study site	p=0.36 for differences in mea age by HL score Not given for logis regression
					D) MULTIPLE TESTS		
23	Haun et al., 2012	United States (English)	378 veterans attending 8 rural and non-rural ambulatory Veteran's Affairs clinics	Inclusion: ≥18 Mean: 61.5 SD: 11.9 Range: 23-89	N (%) with limited HL by age (REALM; S-TOFHLA): Ages ≤59 (n=157): 53 (33.8%); 12 (7.6%) Ages 60-69 (n=123): 46 (37.4%); 16 (13.0%) Ages 70-79 (n=70): 27 (38.6%); 25 (35.7%) Ages ≥80 (n=25): 14 (56.0%); 10 (40.0%) ORs for limited HL (per 10 year increase in age): REALM: OR=1.01 (95% CI: 0.99-1.04)	Gender, ethnic minority status, education, self-reported reading level, retirement status, disability status, diabetes, high blood pressure, stroke	p-values for bivariate statistic (chi-square test) a logistic regression <0.05 for the S-TOFHLA; not significant for the REALM

					S-TOFHLA: OR=1.12 (95% CI: 1.07-1.16)		
24	McNaughton et al., 2011	United States (English)	207 adults presenting to an urban emergency department	Median: 46 IQR: 32-59	Age negatively predicted S-TOFHLA score: standardized regression weight = -0.26; but not REALM score: standardized regression weight = -0.08	Education, gender, race, subjective literacy, subjective numeracy	p<0.05 for S-TOFHLA score; not significant for REALM score
					STUDIES WITH A HIGHER RISK OF BIAS		
					A) TOFHLA AND S-TOFHLA		
25	Aguirre et al., 2005	United States (English and Spanish)	2370 Medicaid and Medicare recipients stratified by ethnicity and language: 936 Non-Hispanic English-speaking; 328 Hispanic English-speaking; 1066 Hispanic Spanish-speaking	Mean: 44.9 for Non-Hispanic English; 31.7 for Hispanic English; 42.7 for Hispanic Spanish	Mean (SD) S-TOFHLA score by age among non-Hispanic English speakers: Ages ≤31: 30 (8.0) Ages 31-45: 28 (8.7) Ages ≥46: 23 (10.5). Scores were similar among Hispanic English speakers, and lower among Hispanic Spanish speakers.	N/A	p<0.001 for mean HL score by age group, within each of the three ethnic/language categories
26	Baker et al., 1998	United States (English)	979 patients with no visual impairments & non-urgent problems from a hospital emergency department serving an indigent African American community	Inclusion: >18 Median: 40	Mean (SD) age by TOFHLA score: Inadequate (n=333): 53.1 (16.0) Marginal (n=122): 43.7 (13.2) Adequate (n=503): 36.2 (11.2)	N/A	<0.001 for mean age in adequate vs. inadequate HL groups
27	Colbert et al., 2013	United States (English)	302 adults taking antiretroviral medication for HIV/AIDS recruited from clinics	Inclusion: ≥18 Mean: 43.9 SD: 7.94	N (%) with limited S-TOFHLA score by age: 20-30 (n=28): 1 (4%); 27 (96%) 31-54 (n=261): 27 (10%); 234 (90%) ≥55 (n=23): 2 (9%); 21 (91%)	N/A	p=0.79 for the proportions with limited HL by age (chi-square test)
28	Downey et al., 2008	United States (English and Spanish)	398 patients with mental capacity to complete the study from 3 outpatient clinics and 1 emergency department	Inclusion: >18	Proportions with limited S-TOFHLA score by age: Ages 43-53 (n=92): 21 (23%) Ages >53 (n=69): 28 (41%)	N/A	0.00 (chi-square test for proportion with limited HL by age)
29	Federman et al., 2009	United States (English and Spanish)	414 community-living adults recruited from community-based settings with no visual impairments	Inclusion: ≥60 Mean: 73.6 SD: 8.6	Age by S-TOFHLA score: Inadequate (n=101): 60-64: 12.9%; ≥85: 12.9% Marginal (n=38):; 60-64: 10.5%; ≥85: 13.2% Adequate (n=275): 60-64: 21.1%; ≥85: 12.7% Proportions across other 5-year age groups varied.	N/A	0.09 for the distribution of HL scores across age categories
30	Geltman et al., 2013	United States (English)	439 Somali refugees living in Massachusetts with no visual or cognitive impairments or disabilities	Inclusion: ≥18 Range: 18-64	N (%) with limited; adequate S-TOFHLA by age: Ages 18-24: 77 (55%); 63 (45%) Ages 25-44: 145 (78%); 41 (22%) Ages ≥45: 104 (92%); 9 (8%)	N/A	p<0.001 for the proportions with limited HL by age (chi-square test)
31	Juzych et al., 2008	United States (English)	204 glaucoma patients from an eye clinic	Inclusion: >18 Mean: 65.8 SD: 12.8	Mean (SD) age by TOFHLA reading score: Lower (n=102):67.1 (13.6) Higher (n=102): 64.6 (12.2)	N/A	0.16 for mean age between HL groups
32	Kalichman et al., 2000	United States (English)	294 adults with HIV/AIDS from AIDS service	Mean: 39.7 SD: 7.4	Mean (SD) age by TOFHLA reading score: Lower (n=50): 39.1 (7.4)	N/A	Not given but non-significant

			organizations and HIV clinics	Range: 24-67	Higher (n=244) was 39.9 (7.3)		
33	Kim, 2009	South Korea (Korean)	103 adults from three community-based senior welfare centres	Inclusion: >60 Mean: 72 SD: 4.91	Mean (SD) age by Korean TOFHLA score: High: 70.98 (4.28) Low: 73.15 (5.14)	N/A	0.022 for mean age between high and low HL groups (general linear model)
34	Mansuco et al., 2006	United States (English and Spanish)	175 patients requiring daily asthma medications from a primary care clinic	Mean: 42.0 SD: 10.0	Proportions with marginal/inadequate TOFHLA score: Ages ≤42: 7% Ages >42: 30%	N/A	<0.0001 for the proportions with limited HL by age
35	Mbaezue et al., 2010	United States (English)	189 diabetic patients from a hospital-based clinic	Inclusion: 18-65 Mean: 51.2 SD: 10	Mean (SD) age by S-TOFHLA score: Limited: 55.79 (8.97) Adequate: 48.23 (9.55)	N/A	p<0.001 for mean age by HL category (t-test)
36	Roth et al., 2005	United States (English)	100 independently-living older adults in an Eldercare community program (85% female)	Mean: 77.5 SD: 8.7 Range: 61-97	Mean TOFHLA scores (not given) did not differ between those aged <75 and ≥75	N/A	Not given but non-significant
37	Schillinger et al., 2002	United States (English and Spanish)	408 patients with type II diabetes from two primary care clinics	Inclusion: >30 Mean: 58.1 SD: 11.4 No range	Mean (SD) age by S-TOFHLA score: Inadequate (n=156): 62.7 (10.9) Marginal (n=54): 59.8 (9.8) Adequate (n=198): 54.0 (10.7)	N/A	<0.001 for mean age between HL groups with ANOVA
38	Williams et al., 1998	United States (English and Spanish)	402 patients with hypertension from one hospital and 114 patients with diabetes from another with no visual impairments or overt psychiatric illness	Inclusion: >18 No mean or range given	Mean (SD) age by TOFHLA score: Hypertension patients: Adequate (n=156): 53.4 (10.2) Marginal (n=50): 57.7 (8.1) Inadequate (n=196): 64.2 (11.3) Diabetes patients: Adequate (n=51): 49.8 (10.3) Marginal (n=13): 53.2 (8.8) Inadequate (n=50): 57.5 (9.3)	N/A	<0.001 for mean age for adequate vs. marginal/inadequate HL groups, among both patient populations
					B) REALM and its short forms		
39	Bains et al., 2011	United States (English)	351 patients from a primary care clinic	Inclusion: ≥18	Proportions of REALM-R scores: ≤6^{th} grade (n=87): 16-34: 12.8%; 35-49: 20.9%; 50-64: 44.2%; ≥65: 22.1% >6^{th} grade (n=260): 16-34: 23.1%; 35-49: 21.6%; 50-64: 32.6%; ≥65: 22.8%	N/A	0.12 for the distribution of HL scores across age categories
40	Cavanaugh et al., 2010	United States (English)	480 incident chronic hemodialysis patients from dialysis clinics	Median: 62 IQR: 51-72	Median (IQR) age by REALM score: <9^{th} grade (n=154): 64.0 (50.2-72.0) ≥9^{th} grade (n=326):60.0 (51.2-71.8)	N/A	0.95 for mean age between HL groups
41	Cox et al., 2011	United Kingdom (English)	127 women with stage I-III breast cancer from an outpatient clinic	Inclusion: ≥18 Median: 64 Range: 34-90	REALM score by age: Ages <65: (n=67): 90% had ≥9^{th} grade score Ages ≥65 (n=60): 93% had ≥9^{th} grade score	N/A	0.45 for the proportion of women with adequate HL
42	Davis et al.,	United States	395 patients from three	Inclusion: ≥18	Mean (SD) age by REALM score:	N/A	<0.001 for mean age

	2006	(English)	outpatient primary care clinics in indigent community population	Mean: 44.8 SD: 13.7 Range: 19-85	≤6th grade (n=75): 50.8 (12.7) 7-8th grade (n=207): 42.6 (13.6) ≥9th grade (n=113): 44.9 (13.5)		between HL categories
43	Ferguson et al., 2011	United States (English)	150 patients with no visual, audial, or cognitive impairments from a YMCA wellness center and a general internal medicine practice	Inclusion: ≥18 Range: 18-88	Age distribution by REALM score: ≤6th grade: 18-39: 9.1%; 40-59: 18.2%; 60-88: 72.7% 7-8th grade: 18-39: 18.2%; 40-59: 20.0%; 60-88: 30.1% ≥9th grade: 18-39: 27.7%; 40-59: 30.1%; 60-88: 42.2%	N/A	0.007 for the proportions with inadequate and adequate HL by age group
44	Gordon et al., 2002	United Kingdom (English)	123 adults with rheumatoid arthritis at a tertiary referral center for rheumatic diseases in a deprived area of Glasgow	Median: 56 Range: 19-77	Median age (range) with <9th grade REALM score: 54 (30-67) Median age (range) with ≥9th grade REALM score: 57 (19-77)	N/A	Not given but non-significant
45	Green et al., 2011	United States (English)	260 patients with chronic hemodialysis from outpatient dialysis clinics	Inclusion: ≥18 Median: 64 Range: 56-73	Median age among <9th grade score (n=41): 61 Median age among ≥9th grade score (n=219): 63	N/A	0.76 for median age between HL categories
46	Ibrahim et al., 2008	United Kingdom (English)	300 coronary heart disease hospital inpatients	Inclusion: ≥18 Mean: 64.0 SD: 12.7 Range: 21-91	Correlation between age and REALM score: 0.001	N/A	0.98 for Spearman's rho
47	Lindau et al., 2002*	United States (English)	529 women from ambulatory obstetrics, gynecology, and women's HIV clinics	Inclusion: ≥18 Median: 27 Range:18-54	Proportions with below adequate REALM score by age: Ages 18-24: 39.5% Ages 25-30: 36.1% Ages 31-39: 37.7% Ages 40-49: 46.5% Ages ≥50: 31.6%	N/A	0.61 for mean HL between age groups (Wilcoxon rank-sum test)
48	McDougall Jr. et al., 2012	United States (English)	45 adults with no dementia from community locations (previously recruited for a memory intervention study)	Inclusion: ≥65 No mean or range given	REALM scores: <9th grade: n=3 ≥9th grade: n=42 Pearson corr. coeff. between age and HL: -0.15	N/A	Not given but non-significant
49	Miller et al., 2007	United States (English)	50 patients at a university-affiliated internal medicine practice	Inclusion: ≥50 No mean or range given	Mean (SD) age by REALM score: <9th grade (n=24): 62.9 (10.5) ≥9th grade (n=26): 62.2 (9.2)	N/A	p=0.78 for mean age by HL category
50	Mosher et al., 2012	United States (English)	310 veterans taking ≥5 non-topical medications with no cognitive impairments from Veteran's Affairs primary care clinics	Inclusion: >65 Mean: 73.9 SD: 5.3	Mean (SD) age by REALM score: ≤6th grade (n=27): 73.2 (5.4) 7-8th grade (n=94): 73.9 (5.5) ≥9th grade (n=189): 74.0 (5.2)	N/A	0.48 for low vs. marginal and adequate groups; 0.52 for adequate vs. low and marginal groups
51	Nokes et al., 2007	United States (English)	489 community-living HIV-seropositive adults from	Mean: 42.6 SD: 8.77	Correlation coefficient between age and REALM score: 0.02	N/A	Not given but non-significant

			infectious disease clinics and community-based organizations in 5 cities	Range: 20-74			
52	Osborn et al., 2010	United States (English)	398 type 1 or 2 diabetes patients from two primary care clinics and two diabetes specialty clinics	Inclusion: 18-85 Mean: 54.4 SD: 13	Mean (SD) age by REALM score: $<9^{th}$ grade (n=120): 55.6 (10.7) $\geq 9^{th}$ grade (n=263): 53.8 (13.9)	N/A	0.15 for mean age between HL groups
53	Peterson et al., 2007	United States (English)	99 primary care patients on Medicaid or Medicare	Inclusion: ≥50 Mean: 59.5 SD: 7.8	Mean (SD) age by REALM score: $<9^{th}$ grade: 60 (8.8) $\geq 9^{th}$ grade: 60 (7.5)	N/A	0.99 for mean age between HL groups (t-test)
54	Shea et al., 2004	United States (English)	1,610 patients from a Veteran's Affairs medical center and three primary care clinics	Inclusion: ≥18 No mean or range given	Mean (SD) REALM score by age group: Ages <45: 58.7 (10.4) Ages 45-64: 57.9 (10.6) Ages ≥65: 55.8 (12.9)	N/A	<0.0005 for mean HL score for ages <45 vs. ≥65 and 45-64 vs. ≥65
55	Stewart et al., 2013	United States (English)	402 daily smokers recruited via media and community outreach	Inclusion: ≥18 Mean: 43.2 SD: 10.8 Range: 18-69	Mean (SD) age by REALM score: $<9^{th}$ grade: 43.21 (10.75) $\leq 9^{th}$ grade: 43.18 (10.82)	N/A	Not given but non-statistically significant
56	Swearingen et al., 2010	United States (English)	194 patients with rheumatic diseases (79% female)	Mean: 56.5 Range: 22-86	Mean (SD) age by REALM score: $<9^{th}$ grade (n=35): 60.8 (12.0) $\geq 9^{th}$ grade (n=159): 55.6 (14.3)	N/A	p<0.05 from Student's t test
57	Zhang et al., 2009	Singapore (English)	199 patients with rheumatic diseases and no cognitive problems from a referral centre	Inclusion: >18 Ages not given	Mean (SD) age by REALM score: $<9^{th}$ grade (n=87): 43.7 (14.0) $\geq 9^{th}$ grade (n=112): 48.5 (14.7)	N/A	0.04 for mean age between HL groups
					C) MULTIPLE TESTS		
58	Kirk et al., 2012	United States (English)	563 community-based African American, American Indian, and white adults with diabetes	Inclusion: ≥60	Mean (SD) S-TOFHLA; REALM-SF; NVS by age: Ages 60-69: 51.2 (12.4); 5.9 (1.8); 3.5 (1.9) Ages 70-79: 48.8 (13.8); 6.1 (1.7); 3.2 (2.0) Ages ≥80: 42.6 (12.3); 6.0 (1.4); 3.3 (1.7)	N/A	<0.05 for S-TOFHLA scores between 60-69 and 80+ year olds. No age differences in REALM-SF or NVS.
59	Ozdemir et al., 2010	Turkey (Turkish)	456 patients with no cognitive impairments from a primary care clinic	Mean: 36.21 SD: 12.61 Range: 17-72	Mean (SD) REALM score; NVS score by age: Ages 15-24: 62.2 (3.1); 3.8 (1.5) Ages 25-34: 62.2 (4.4); 2.7 (1.2) Ages 35-44: 59.2 (8.9); 2.0 (1.8) Ages ≥45: 57.8 (7.4); 2.2 (1.7)	N/A	0.000 for mean HL scores between age groups for both tests (ANOVA)
60	Walker et al., 2010	United States (English)	21 hospital inpatients and 34 outpatients who were able to see, answer questions appropriately, with stable medical status	Mean: 56.8 SD: 13.6	Pearson corr. coefficient between age and REALM score: 0.08; between age and TOFHLA score: -0.12.	N/A	Not given but non-significant

6.3.2.2 Study designs and populations

Although study designs varied, age and health literacy were analysed cross-sectionally in all studies. Study populations were healthy, community-dwelling adults (11/60; 18%) (R. J. Adams et al., 2009; Connor et al., 2013; Federman et al., 2009; Gazmararian et al., 1999; Jackson & Eckert, 2008; Kim, 2009; McDougall, Mackert, & Becker, 2012; Roth & Ivey, 2005; Stewart et al., 2013; Sudore et al., 2006; von Wagner et al., 2007), community-dwelling outpatients recruited in health care settings (18/60; 30%) (Bains & Egede, 2011; Calkins Aguirre et al., 2005; Carthery-Goulart et al., 2009; Chew et al., 2004; Davis et al., 2006; Ferguson, Lowman, & DeWalt, 2011; Haun, Luther, & Dodd, 2012; Jovic-Vranes, Bjegovic-Mikanovic, & Marinkovic, 2009; Jovic-Vranes, Bjegovic-Mikanovic, Marinkovic, & Kocev, 2011; Jovic-Vranes & Bjegovic-Mikanovic, 2012; Lindau et al., 2002; Miller et al., 2007; Mosher, Lund, Kripalani, & Peter, 2012; Ozdemir, Alper, Uncu, & Bilgel, 2010; Peterson et al., 2007; Shah, West, Bremmeyr, & Savoy-Moore, 2010; Shea et al., 2004), chronic disease patients (23/60; 38%) (Armistead-Jehle et al., 2010; Cavanaugh et al., 2010; Colbert, Sereika, & Erlen, 2013; Cox, Bowmer, & Ring, 2011; M.-M. Gordon, Hampson, Capell, & Madhok, 2002; Green et al., 2011; Ibrahim et al., 2008; Juzych et al., 2008; Kalichman, Benotsch, Suarez, Catz, & Miller, 2000; Kirk et al., 2012; Laramee, Morris, & Littenberg, 2007; Levinthal et al., 2008; Mancuso & Rincon, 2006; Mbaezue et al., 2010; Morrow et al., 2006; Nokes et al., 2007; Osborn et al., 2010; Robinson et al., 2011; Rowlands et al., 2013; Schillinger et al., 2002; Swearingen et al., 2010; M. Williams et al., 1998; Zhang, Li, Fong, & Thumboo, 2009), emergency department/acute care inpatients (5/60; 8%) (D. W. Baker et al., 1998; Ginde, Weiner, Pallin, & Camargo, 2008; McNaughton, Wallston, Rothman, Marcovitz, & Storrow, 2011; N. S. Morris, Grant, Repp, Maclean, & Littenberg, 2011; Olives, Patel, Patel, Hottinger, & Miner, 2011), and a refugee population (1/60; 2%; Table 6.2). Two studies had samples consisting of hospital inpatients and outpatients (Downey & Zun, 2008; Walker, Pepa, & Gerard, 2010).

All studies used “convenience” samples except for two that aimed to recruit samples representative of the general population (Adams et al., 2009; von Wagner et al., 2007). Studies sampling from emergency room patients and acute care hospital inpatients excluded those who were too ill or distressed to participate. Only half of all studies reported participation rates (median reported rate = 87%; range: 26%–98%). Sample sizes ranged from 44 to 3260; eight studies had <100 participants.

6.3.2.3 Health literacy measurements

Thirty-six studies (60%) assessed health literacy using the TOFHLA or S-TOFHLA in the original or a translated or culturally adapted version (Table 6.2). Two of these (Calkins Aguirre et al., 2005; Connor et al., 2013) stratified their study populations by ethnicity and language (Calkins Aguirre et al., 2005) or by language (Connor et al., 2013) to give three analyses each, for a total of 40 analyses in 36 studies using the TOFHLA or S-TOFHLA. Twenty-six studies (43%) assessed health literacy using the REALM or one of its short forms (Table 6.2). Four studies used the NVS (R. J. Adams et al., 2009; Kirk et al., 2012; Ozdemir et al., 2010; Shah et al., 2010). Three used both the TOFHLA and the REALM (Haun et al., 2012; McNaughton et al., 2011; Walker et al., 2010), one used the REALM and the NVS (Ozdemir et al., 2010), and one used all three instruments (Kirk et al., 2012). Therefore, a total of 70 analyses were performed in the 60 studies included in the narrative review. The three separate analyses in Connor et al.'s 2013 study were collapsed by the authors for the meta-analysis, to give a total of 29 analyses in 31 studies in the meta-analysis.

6.3.3 Overview of study results

6.3.3.1 Narrative review

Overall, 41/70 analyses (59%) observed a statistically significant inverse association between age and health literacy. This association was more frequently observed in analyses using the S-TOFHLA/TOFHLA (32/40; 80%) and NVS (3/4; 75%) than in those using the REALM (6/26; 23%); a statistically significant difference (χ^2 (2) = 21.51, p<0.001). Twenty-two out of 28 (79%) analyses presenting a multivariable-adjusted measure of association between age and health literacy compared with 19/42 (45%) analyses presenting an unadjusted association observed a statistically significant inverse relationship (χ^2 (1) = 7.69, p=0.006). This finding may be in part a methodological artefact, as several studies that observed a non-significant result in unadjusted analysis did not go on to include age in multivariable modelling. The likelihood of observing a statistically significant result did not differ by participation rate (Kruskal–Wallis χ^2 (1) = 0.067, p=0.80) or by whether a participation rate was reported (χ^2 (1) = 0.11, p=0.74). Among studies that compared mean age across health literacy score categories, 6/8 (75%) that used the TOFHLA or S-TOFHLA observed that adults in lower health literacy categories had a higher mean age, compared with 3/12 (25%) studies that used the REALM (χ^2 (1) = 4.85, p=0.028).

6.3.3.2 Meta-analysis

The meta-analysis of 29 individual analyses gave an overall fixed-effects OR of 2.33 (95% CI: 2.12–2.56) for the association between older age and limited health literacy. The *Q* value was 274.68 (df = 28; p<0.0001) and I^2 statistic was 89.81, indicating that significant heterogeneity within the fixed-effects results and that results from the random-effects model (OR = 2.56; 95% CI: 1.85–3.53) are appropriate for interpretation. Within studies using the S-TOFHLA/TOFHLA, the fixed-effects OR was 4.44 (95% CI: 3.89–5.06). The *Q* value was 77.70 (df = 18; p<0.0001) and I^2 statistic was 76.83, indicating significant heterogeneity and that results from the random-effects model (OR = 4.20; 95% CI: 3.13–5.64) are again appropriate for interpretation. Within studies using the REALM, the fixed-effects OR was 1.20 (95% CI: 1.05–1.37), with a *Q* value of 9.40 (df = 9; p=0.40) and I^2 statistic of 4.26, indicating that heterogeneity may not be important. The random-effects OR was 1.19 (95% CI: 1.03–1.37). In this instance, the fixed- and random-effects ORs were negligibly different; I selected the random-effects OR for interpretation to be conservative and consistent with reporting. Figure 6.2 shows a forest plot and individual study statistics for the random-effects meta-analyses.

A sensitivity analysis removing one study at a time showed that no individual study exerted significant influence over the pooled result. The second sensitivity analysis removing all studies using age cut-offs other than age 65 showed similar results to the main analysis. In this analysis, the random-effects OR for limited health literacy was 4.23 (95% CI: 2.86–6.27) within studies using the S-TOFHLA/TOFHLA and was 1.31 (95% CI: 1.10–1.57) within studies using the REALM.

Group by Health literacy test	Study name	Age comparison	Odds ratio	Lower limit	Upper limit	Z-Value	p-Value
REALM	Lindau	50+ vs. <50	0.715	0.268	1.913	-0.667	0.504
REALM	Ferguson	60+ vs. <60	1.344	0.646	2.797	0.791	0.429
REALM	Bains	65+ vs. <65	0.952	0.530	1.710	-0.165	0.869
REALM	Cox	65+ vs. <65	0.612	0.170	2.205	-0.750	0.453
REALM	Kirk2	65+ vs. <65	1.288	0.723	2.297	0.859	0.390
REALM	Ozdemir	65+ vs. <65	0.707	0.210	2.381	-0.560	0.575
REALM	Shea	65+ vs. <65	1.452	1.182	1.784	3.547	0.000
REALM	Walker2	65+ vs. <65	0.592	0.160	2.184	-0.788	0.431
REALM	Sudore	77+ vs. <77	1.050	0.841	1.311	0.430	0.667
REALM	Haun2	80+ vs. <80	1.185	0.517	2.716	0.401	0.688
REALM			1.185	1.025	1.370	2.293	0.022
TOFHLA	Mancuso	42+ vs. <42	5.661	2.195	14.599	3.587	0.000
TOFHLA	Jovic-Vranes 2009	44+ vs. <44	4.860	2.410	9.800	4.418	0.000
TOFHLA	Geltman	45+ vs. <44	5.413	2.636	11.118	4.599	0.000
TOFHLA	Downey	53+ vs. <53	3.329	1.902	5.828	4.210	0.000
TOFHLA	Colbert	55+ vs. 20-54	0.854	0.190	3.834	-0.206	0.837
TOFHLA	Aguirre	65+ vs. <65	20.761	9.864	43.694	7.989	0.000
TOFHLA	Carthery-Goulart	65+ vs. <65	2.779	1.562	4.947	3.475	0.001
TOFHLA	Chew	65+ vs. <65	3.700	1.695	8.076	3.285	0.001
TOFHLA	Connor	65+ vs. <65	10.804	6.737	17.326	9.877	0.000
TOFHLA	Ginde	65+ vs. <65	1.736	0.913	3.298	1.684	0.092
TOFHLA	Jovic-Vranes 2011	65+ vs. <65	4.250	3.261	5.539	10.703	0.000
TOFHLA	Kirk1	65+ vs. <65	2.427	1.483	3.971	3.529	0.000
TOFHLA	Laramee	65+ vs. <65	3.510	2.184	5.641	5.188	0.000
TOFHLA	Morris	65+ vs. <65	4.538	1.912	10.770	3.429	0.001
TOFHLA	von Wagner	65+ vs. <65	6.300	3.304	12.014	5.589	0.000
TOFHLA	Walker1	65+ vs. <65	1.339	0.396	4.521	0.470	0.638
TOFHLA	Haun1	80+ vs. <80	7.132	3.073	16.554	4.573	0.000
TOFHLA	Federman	85+ vs. 65-69	1.420	0.667	3.027	0.909	0.363
TOFHLA	Gazmararian	85+ vs. <85	8.620	5.552	13.384	9.596	0.000
TOFHLA			4.204	3.131	5.644	9.550	0.000

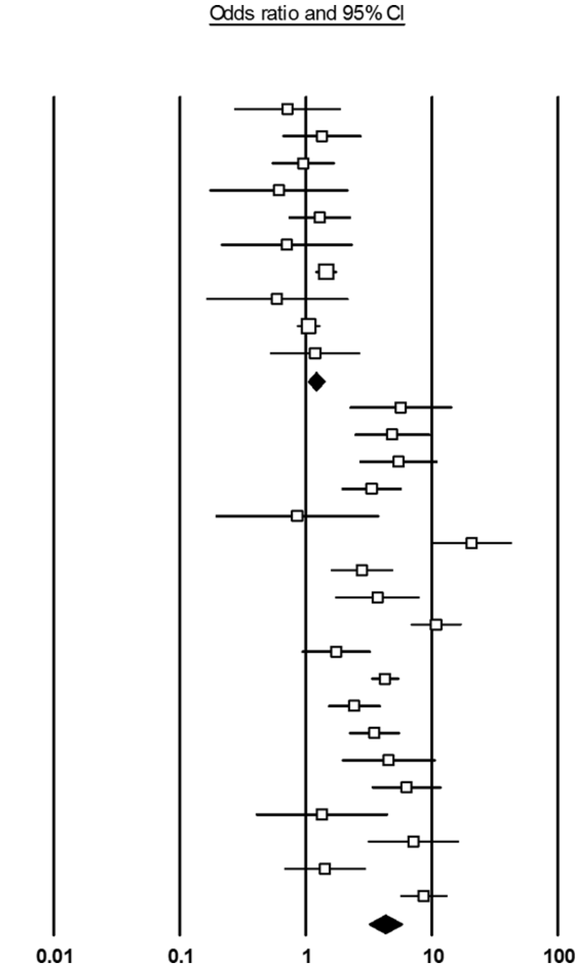

Figure 6.2 Forest plot of random-effects pooled odds ratios for the association between older age and limited health literacy, stratified by health literacy test

6.3.3.3 Meta-regression

A random-effects meta-regression model showed that health literacy test was influential on the pooled estimate (Table 6.3). Studies using the S-TOFHLA/ TOFHLA had, on average, an OR of 4.44 (95% CI: 1.75–5.53) higher than that of studies using the REALM to assess health literacy. The health status of study populations, whether socioeconomic status and/or cognitive impairment was adjusted for, country of study, language of study, and participation rate were not modifiers of the relationship between age and health literacy (Table 6.3). The τ^2 statistic, which indicates the amount of residual between-study variance after accounting for these variables, was 0.22.

Table 6.3 Random effects meta-regression for influence of study characteristics on pooled result

Study characteristic	Coefficient	95% CI	Standard error	*p*-value
Health literacy test				
REALM	1.00	(ref)	(ref)	(ref)
TOFHLA/STOFHLA	4.44	1.75, 5.53	1.34	<0.0001
Health status of study population				
Healthy, community dwelling	1.00	(ref)	(ref)	(ref)
Chronic disease patients	0.57	0.29, 1.13	1.40	0.11
Community-dwelling outpatients	0.92	0.53, 1.60	1.32	0.77
Acute care patients	0.46	0.20, 1.06	1.54	0.07
Adjusted for socioeconomic or cognitive factors				
No	1.00	(ref)	(ref)	(ref)
Yes	1.13	0.64, 1.99	0.79	0.68
Country of study				
United States	1.00	(ref)	(ref)	(ref)
Other	0.92	0.52, 1.65	1.34	0.84
Language of study				
English	1.00	(ref)	(ref)	(ref)
Other	0.94	0.53, 1.67	1.34	0.84
Participation rate reported				
No	1.00	(ref)	(ref)	(ref)
Yes	1.21	0.76, 1.92	1.26	0.42

6.3.3.4 Publication bias

The classic fail-safe *N* was 2,080, indicating that this number of theoretically unpublished studies with null results would have to exist in order to attenuate the overall pooled effect estimate to the null. The funnel plot showed reasonable symmetry, although studies with larger lnOR values tended to have larger standard errors (Figure 6.3). Duval and Tweedle's "fill and trim" method imputed four additional studies to produce symmetry in the graph (Figure 6.3). The imputed overall pooled random-effects OR that takes publication bias into account was 3.01 (95% CI: 2.19–4.13). This imputed OR is more extreme in magnitude, but not significantly different to the original overall random-effects OR of 2.56 (95% CI: 1.85–3.53).

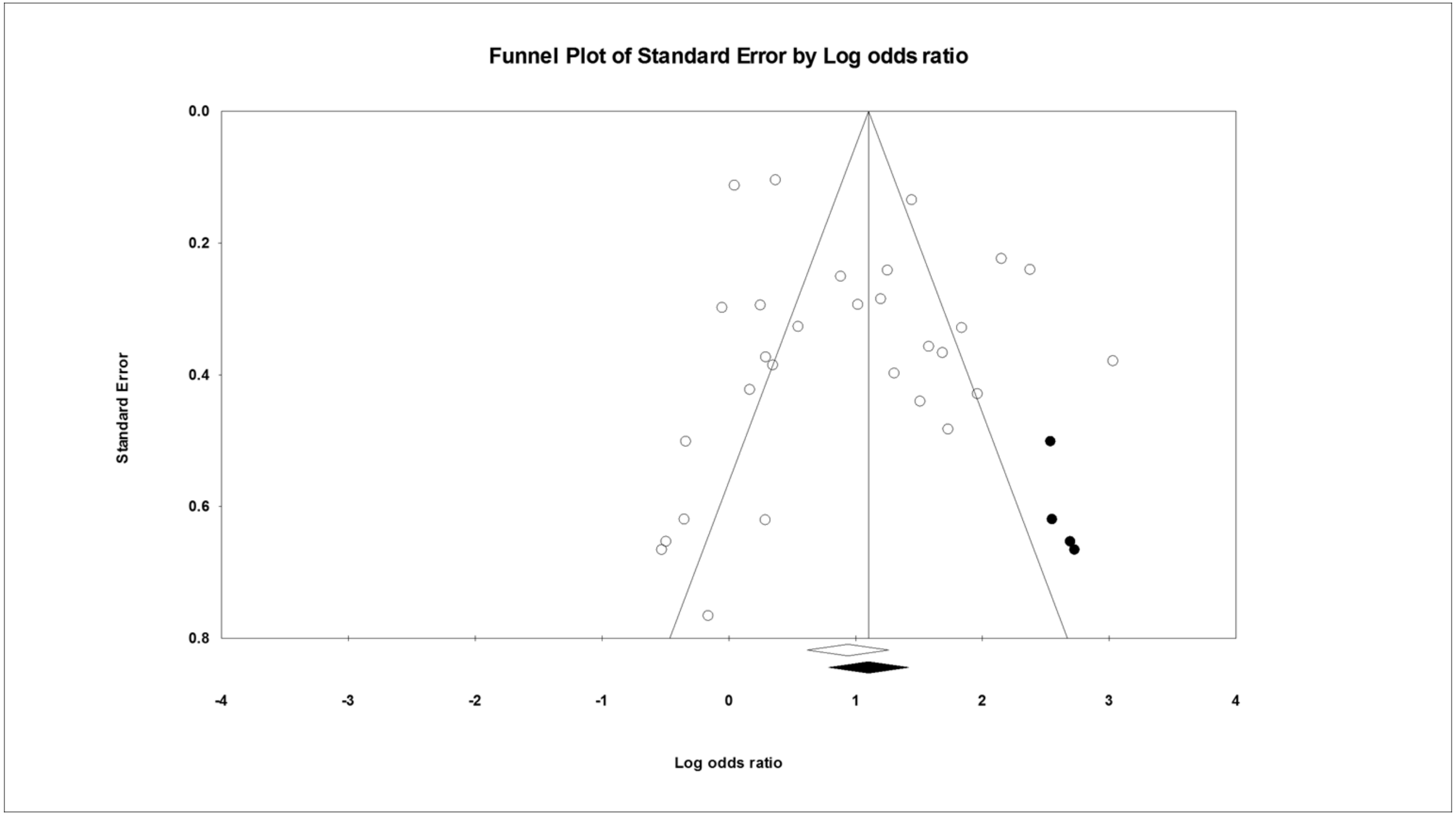

Figure 6.3 Funnel plot of standard error by log odds ratio to assess publication bias, with studies imputed using the 'trim and fill' method shown in black

6.3.3.5 The mediating role of cognitive function

Only five studies adjusted for cognitive function when assessing the relationship between age and health literacy (Armistead-Jehle et al., 2010; Chew et al., 2004; Gazmararian et al., 1999; Levinthal et al., 2008; Morrow et al., 2006). Two of these studies adjusted for the fluid cognitive functions of speech comprehension, processing speed, working memory, and listening span, along with visual and auditory function (Levinthal et al., 2008; Morrow et al., 2006). Data from these studies were not available for inclusion in the meta-analysis, but they provide important insights into the influence of cognitive function on health literacy skills during ageing. Levinthal and colleagues (2008) observed that age was no longer significantly associated with health literacy after accounting for cognitive and sensory variables in their linear regression model predicting S-TOFHLA score. In contrast, Morrow and colleagues (2006) observed that age differences in health literacy were explained by educational differences within their sample and not by cognitive or sensory function in their regression model predicting S-TOFHLA score. However, each of the cognitive functions assessed was a strong predictor of S-TOFHLA score, regardless of age (βs ranged from 0.39 to 2.08, all with $p<0.001$). The three other studies adjusted for age-related cognitive impairment as measured by the Mini-Mental State Examination (MMSE) and Mini-Cog, but did not observe complete attenuation of the association between age and TOFHLA-assessed health literacy (Armistead-Jehle et al., 2010; Chew et al., 2004; Gazmararian et al., 1999). One study observed some attenuation of the age–health literacy association from OR = 5.9 (95% CI: 2.8–12.5) to OR = 3.7 (95% CI: 1.7–8.1) after adjustment for cognitive impairment, educational attainment, and employment status (Chew et al., 2004). The degree of attenuation of the age–health literacy relationship by cognitive impairment in the other two studies is unascertainable, as neither presented the crude measures of association prior to adjustment for cognitive impairment.

6.4 Discussion

My findings are consistent with a narrative review on the prevalence of limited health literacy in the United States, which observed older adults to be more likely than younger adults to have limited health literacy (Paasche-Orlow et al., 2005). In my review, older age was strongly associated with having limited health literacy in studies that assessed health literacy as reading comprehension, reasoning, and numeracy skills, using the TOFHLA or S-TOFHLA. However, older age was not associated with health literacy, when assessed as medical vocabulary using the

REALM. These findings suggest that ageing-related health literacy decline occurs primarily with skills requiring fluid, rather than crystallised cognitive functions.

6.4.1 The role of cognitive function

The role of cognitive function in age-related health literacy differences is not yet well understood. Although MMSE and S-TOFHLA scores have been strongly positively associated among older adults, independently of age (D. W. Baker et al., 2002; Dahlke et al., 2014; Federman et al., 2009), cognitive impairment according to the MMSE did not explain why health literacy tended to decrease with increasing age in the few studies reviewed here. The two studies that assessed the mediating roles of fluid cognitive and sensory functions in the relationship between age and health literacy showed conflicting results (Levinthal et al., 2008; Morrow et al., 2006). However, based on the evidence showing relationships between cognitive function and functional health literacy (Murray et al., 2011; Reeve & Basalik, 2014; Wolf et al., 2012), and longitudinal decline in fluid cognitive functions during ageing (O'Carroll, 1995; Salthouse, 2009; Singh-Manoux et al., 2012), it seems probable that cognitive ageing plays a role in functional health literacy decline. Factors related to cognition, such as cognitive reserve, may also affect health literacy skills during ageing. Practices that can help to improve or maintain cognition during ageing, such as social engagement and physical activity may help with the maintenance of health literacy skills (Sofi et al., 2011; Thomas, 2011a). Longitudinal research is needed to determine the extent to which ageing-related cognitive decline may explain health literacy decline, in addition to other possible processes.

6.4.2 Limitations

All included analyses were cross-sectional and therefore could not assess the temporality of the association between ageing and health literacy. The majority of studies were judged to be of a higher risk of bias, as most did not adjust for potential confounders. Selection bias may be present in individual studies if the reasons for non-response are related to age or health literacy. The degree to which any cumulative selection bias across studies has influenced the results of this review is difficult to ascertain. Several studies excluded adults with cognitive impairment, which limited my ability to assess the role of cognitive impairment in age-related health literacy differences. Studies that analysed health literacy score using continuous measures of association could not be included. Standardized mean difference statistics that would be used to pool continuous effect measures assume that variability in health literacy scores is due to scale differences, rather than due to true variation in health literacy across study populations, an assumption that is unlikely to be true. In these instances, I contacted the study authors to obtain the data in a format useable for the purpose of this meta-analysis, with reasonable success (response from 8/16 authors). I was limited to studies published in English, although the included studies were conducted in nine different countries and languages. Finally, few studies investigated the role of cognitive function, which prevented me from drawing firm conclusions about this complex relationship.

6.4.3 Strengths

This review adhered to the PRISMA guidelines for systematic review reporting (Moher et al., 2009) and closely followed guidelines in the Cochrane Handbook (The Cochrane Collaboration, 2011). At the time of conducting the systematic review and meta-analysis, I was not aware of any previous quantitative synthesis of data on ageing and health literacy. I excluded studies solely comprising individuals with diagnosed mental health and cognitive impairments. However, studies that included some adults with cognitive impairments were eligible, as I aimed to capture variability in cognitive function in order to assess its mediating role in the age–health literacy relationship. I used the well-defined and clinically relevant outcome of ‘limited health literacy’, allowing the examination of not only whether older adults had lower health literacy than younger adults, but also how much more likely they were to be below this threshold. Although the majority of studies were judged to be of a higher risk of bias, my meta-regression analysis did not identify adjustment for socioeconomic factors or cognitive impairment, or low/non-reporting of participation rates as influential factors over the pooled point estimate.

6.4.4 Conclusions

This systematic review and meta-analysis indicates that the ‘fluid’ health literacy skills assessed by the TOFHLA/S-TOFHLA may decline with age, while the ‘crystallised’ health literacy skills assessed by the REALM may be more stable with age. This finding, while consistent, does not provide prospective evidence for the role of older age in reduced health literacy, or insight into the cognitive mechanisms that may affect health literacy during ageing. Further chapters in this thesis using data from the English Longitudinal Study of Ageing will be valuable for providing within-person longitudinal data on ‘fluid’ functional health literacy skills over time, alongside sociodemographic, cognitive, and behavioural variables.

Chapter 7. Methodology of the English Longitudinal Study of Ageing

7.1 Overview

The English Longitudinal Study of Ageing (ELSA) is a longitudinal panel survey, which began in 2002, of English adults aged 50 years and over (Marmot, Banks, Lessof, & Nazroo, 2003; Steptoe, Breeze, Banks, & Nazroo, 2013a). The researchers collect data every two years. At the time of writing this thesis, a decade of ELSA data was available in six data collection waves, from 2002 to 2013. The ELSA is a multidisciplinary study that aims to capture the economic, social, psychological, cognitive, and other health-related changes that occur during ageing in England. The ELSA is a collaborative project, with a team of researchers from the Department of Epidemiology and Public Health at UCL, the Institute for Fiscal Studies (IFS), the University of Manchester, and the National Centre for Social Research (NatCen). The ELSA is designed to be the ‘sister’ study to the Health and Retirement Study (HRS) in the United States, and hence shares many design and survey similarities with the HRS.

7.2 Funding

The National Institute of Aging in the United States (grant numbers 2RO1AG7644-01A1, 2RO1AG017644) and a consortium of UK government departments coordinated by the Office for National Statistics fund the ELSA.

7.3 Ethics

The London Multicentre Research Ethics Committee provided ethical approval of the project (MREC/01/2/91). All participants provided informed consent.

7.4 Sampling strategy

Wave 1 of the ELSA (2002/03; baseline) sampled from households that had previously responded to the Health Survey for England (HSE) in 1998, 1999, and 2001 (Taylor et al., 2007). The HSE is based on a random stratified sample of all households in England. In brief, eligible participants for the ELSA cohort came from HSE households and were aged ≥50 years (the ‘core’ sample), or, were a partner living with the core sample member at the time of HSE who were not age-eligible at the time of the HSE or who had joined the household since the HSE interview (Taylor et al., 2007). Refreshment samples have been drawn from the HSE for wave

3 of ELSA (from HSE 2001/02/03/04) wave 4 of ELSA (HSE 2006), and wave 6 of ELSA (HSE 2009/10/11) to account for the ageing structure of the original core sample.

7.5 Sample types

The ‘core’ sample members of ELSA were the eligible individuals identified and recruited from the HSE. There are four other types of ELSA sample members: core partners, younger partners, older partners, and new partners.

- **Core partners**: core members’ partners and spouses, who lived in the same household as the core member at the time of the HSE interview and were age-eligible for the ELSA. They were added to the sample at waves 1, 3, 4, and 6.
- **Younger partners**: core members’ partners and spouses, who lived in the same household as the core member at the time of the HSE interview and still cohabited with the core member at the time of the ELSA interview, but were aged less than 50 years.
- **Older partners**: core members’ partners and spouses, who lived in the same household as the core member at the HSE interview and still lived in the same household as the core member at the ELSA interview, but were aged over 53 years (in wave 3), 75 years or above (in wave 4), or over 55 years (in wave 6).
- **New partners**: core members’ partners or spouses at the time of any ELSA interview, but had newly joined the household since the original HSE interview.
- **Sample members:** a small group of people in the dataset who are neither core members nor partners. The sample members were originally eligible to be core members of the ELSA, but were included at a later wave as they lived in the same household as an ELSA respondent but were not the respondent’s partner or spouse. In most cases, the sample members were the sibling, child, or parent of a core member.

All analyses in this thesis used data from the core members only. The partners and other sample members are only described in this chapter because they are included in the overall sample sizes and response rates that are calculated for the ELSA.

7.6 Data collection

Data are collected biennially in data collection ‘waves’. At present, there have been six waves of data collection, encompassing a decade: wave 1 (2002/03), wave 2 (2004/05), wave 3 (2006/07), wave 4 (2008/09), wave 5 (2010/11), and wave 6 (2012/13). In-person interviews are conducted in the participants’ homes, using computer-aided personal interviewing (CAPI). The interviews capture information on sociodemographic factors, work, retirement, housing, income, and assets. Participants also complete a paper-based self-completion questionnaire that they mail back following the in-person interview. The self-completion questionnaire captures information on health behaviours, social engagement, psychological well-being, and expectations about the future. Proxy interviews with a close family member or friend are conducted if the participant is unable to respond due to physical or mental ill health; or a cognitive impairment; or if they were in hospital or temporary care. At all existing waves, participants with proxy interviews were more likely to be older, to have a limiting long-standing illness, and were less likely to be in paid work than non-proxy respondents. Excluding the small number of proxy respondents is unlikely to affect results for most analyses (NatCen Social Research, 2014).

At waves 2, 4, and 6, data collection included a separate at-home visit from a trained research nurse to collect blood and urine samples for biomarker measurements; objective height and weight measurements to calculate body mass index; and physical function measures such as timed walk and sit-to-stand tests.

7.7 Response rates

Wave 1 fieldwork ran from March 2002 to March 2003. The individual response rate was 67%, with a sample size of 12,100 (Marmot et al., 2003; NatCen Social Research, 2014). The sample included 11,392 core members, 636 younger partners, and 72 new partners.

Wave 2 fieldwork ran from June 2004 to July 2005. From the original sample, wave 2 included 8780 core members, 57 core partners, 501 younger partners, and 94 new partners. In total, wave 2 included 9432 respondents.

Wave 3 fieldwork ran from May 2006 to August 2007. From the original sample, wave 3 included 7735 core members, 91 core partners, 312 younger partners, 74 new partners (from previous waves) and 26 new partners (found this wave). From the new refreshment sample, wave 3 included 1275 core members, 142 older partners, 295 younger partners, and 21 new partners. In total, wave 3 included 9971 respondents, 9010 of whom were core members.

Wave 4 fieldwork ran from May 2008 to July 2009. From the original sample, wave 4 included 6623 core members, 101 core partners, 276 younger partners, 98 new partners (from previous waves), 21 new partners (found this wave). From the refreshment sample at wave 3, wave 4 included 972 core members, 12 core partners, 106 older partners, 226 younger partners, 14 new partners (from wave 3), and 11 new partners (found this wave). From the new refreshment sample, wave 4 included 2291 core members, 119 younger partners, and 15 new partners (found this wave). In total, wave 4 included 11050 respondents, 9886 of whom were core members.

Wave 5 fieldwork ran from June 2010 to July 2011. From the original sample, wave 5 included 6242 core members, 125 core partners, 116 new partners (from previous waves), and 9 new partners (found this wave). From the refreshment sample at wave 3, wave 5 included 936 core members, 17 core partners, 102 older partners, 217 younger partners, 26 new partners (from previous waves), and 10 new partners (found this wave). From the wave 4 refreshment sample, wave 5 included 1912 core members, 27 core partners, 127 older partners, 101 younger partners, 14 new partners (from wave 4), and 12 new partners (found this wave). In total, wave 5 included 10274 respondents, 9090 of whom were core members.

Wave 6 fieldwork ran from May 2012 to June 2013. From the original sample, wave 6 included 5659 core members, 123 core partners, 267 younger partners, 109 new partners (from previous waves), and 10 new partners (found this wave). From the wave 3 refreshment sample, wave 6 included 888 core members, 15 core partners, 93 older partners, 193 younger partners, 33 new partners (from previous waves), and 3 new partners (found this wave). From the wave 4 refreshment sample, wave 6 included 1796 core members, 109 older partners, 91 younger partners, 22 new partners (from waves 4 and 5), and 7 new partners (found this wave). From the new refreshment sample, wave 6 included 826 core members, 144 older partners, 146 younger partners, 28 core partners, and 10 new partners. There were 29 sample members who lived with core members at this wave. In total, wave 6 included 10601 respondents, 9169 of whom were core members.

Figure 7.1 shows the study flow for core members recruited in the original sample at wave 1. Note that when any of waves 3 through 6 are taken cross-sectionally or longitudinally forward, the number of core members is larger than shown here, due to the refreshment waves.

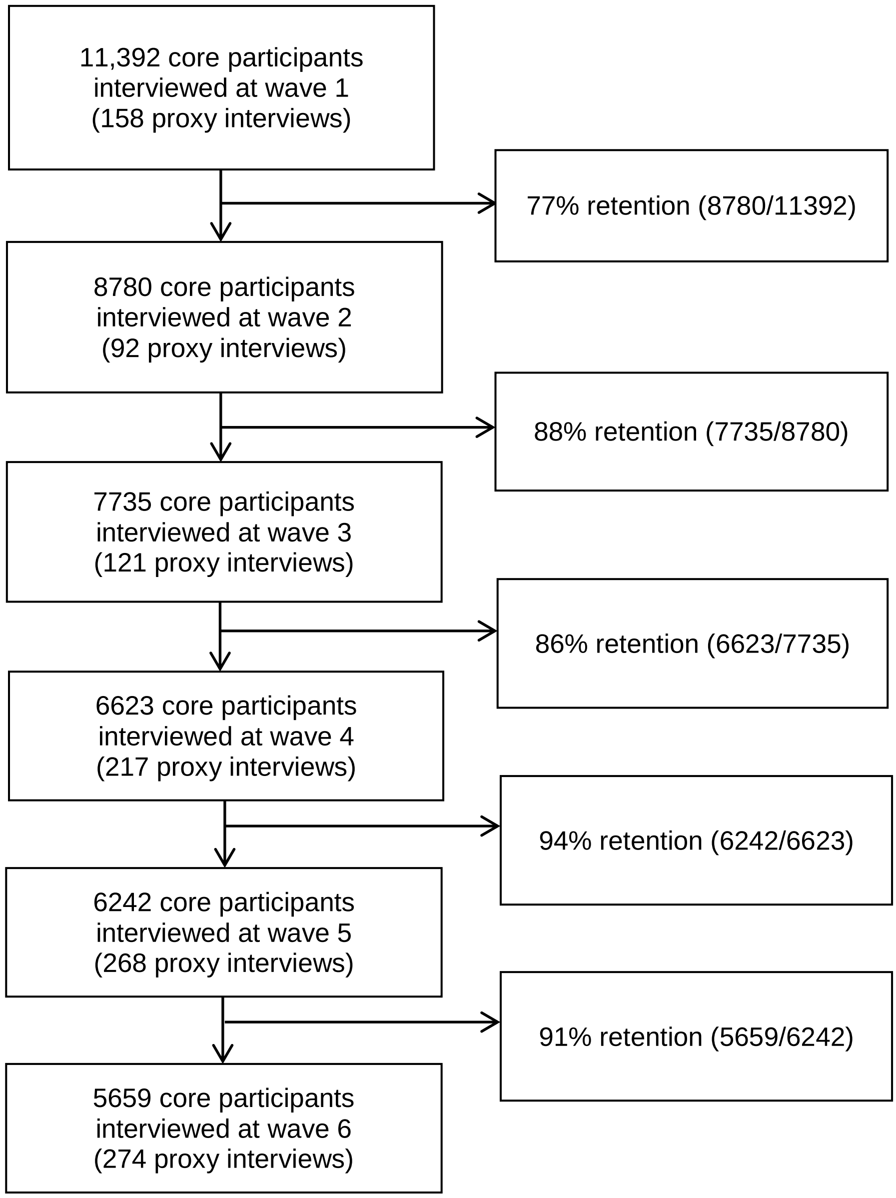

Figure 7.1 Study flow of ‘core’ ELSA participants from waves 1 to 6

7.8 Weighting

Population-based weights are available for all core participants in the ELSA sample. The weights are intended to account for non-population representativeness of the ELSA sample due to differential response to the study, and for any bias in results caused by non-response or drop-out over time. The weights were developed by examining the different stages of study non-response and drop-out, and the extent of drop-out at each stage. Using logistic regression modelling with HSE data, the demographic, health-related, social, and geographic factors associated with non-response and drop-out to the ELSA were examined and the weights were calculated as the inverse of estimated probability of responding for a given participant. At wave 1, a ‘calibration-weighting’ technique was additionally used to ensure that the weighted sample of respondents matched the target population of interest, defined as all adults aged 50 and over in England living in private households in 2001, according to the 2001 Census (NatCen Social Research, 2014; Taylor et al., 2007).

Cross-sectional weights are available at each wave, while longitudinal weights are also available at waves 3 through 6. The longitudinal weights are created for all core participants who were present in every single data collection wave and remained living in private households. Consequently, while participants could come out of the study and back in again for the sample sizes shown in the previous section, the sample sizes for the longitudinal weights are more restrictive: 7168 for the wave 3 longitudinal weight sample, 5971 for the wave 4 longitudinal weight sample, 5262 for the wave 5 longitudinal weight sample, and 4711 for the wave 6 longitudinal weight sample.

7.9 Overview of the data used in this thesis

Chapters 8 through 11 of this thesis use data from the ELSA for empirical studies on health literacy during ageing and implications for health behaviour. Because health literacy was assessed in the ELSA at waves 2 (2004/05) and 5 (2010/11), these two waves of data collection are the most important for this thesis. Chapter 8 (Study 2) links wave 2 (‘baseline’) and wave 5 (‘follow-up’) to examine changes in health literacy scores between the two waves; the sociodemographic predictors of health literacy decline; and the roles of cognitive function and cognitive decline in ageing-related health literacy decline. Chapter 9 (Study 3) uses data from all of waves 2, 3, 4, and 5 to examine the roles of sustained Internet use and social engagement in potentially protecting against health literacy decline during ageing.

Chapter 10 (Study 4) then uses two different cuts of the data. The first links waves 5 and 6 to examine the role of low health literacy at wave 5 in predicting colorectal cancer screening uptake at wave 6. The second cut then links waves 2, 5, and 6 to examine the role of health literacy decline between waves 2 and 5 in predicting colorectal cancer screening at wave 6. Chapter 11 (Study 5) then uses data from all of waves 2, 3, 4, 5, and 6 to examine the roles of health literacy at wave 2 and health literacy decline between waves 2 and 5 in predicting the consistent maintenance of health-promoting lifestyle behaviours (i.e. weekly moderate-to-vigorous physical activity; adequate fruit and vegetable intake; non-problematic drinking, and non-smoking) from waves 2 through 6.

The data used throughout this data are drawn from the in-person CAPI study interview and the self-completion questionnaire at various waves of data collection. None of the data from proxy interviews or nurse visits are used in this thesis. The data on Internet use and social engagement in Chapter 9 (Study 3) and on fruit and vegetable intake and alcohol consumption in Chapter 11 (Study 5) came from the self-completion questionnaire. All other data for the studies, including all sociodemographic factors, health literacy, cognitive function, cancer screening uptake, physical activity, and smoking, came from the in-person CAPI study interviews. The Methods sections of the individual empirical chapters describe in more detail the specific wordings of the interview and questionnaire questions, and the analytical variables derived from them.

Chapter 8. Study 2: Cognitive function and health literacy decline during ageing[4]

8.1 Background

In a systematic review and meta-analysis of the existing literature, the first empirical chapter of this thesis indicated that the 'fluid' health literacy skills assessed by the TOFHLA may decline with age, while the 'crystallised' health literacy skills assessed by the REALM appear to be stable with age. All of the studies included in the meta-analysis were cross-sectional, most did not adjust for potentially confounding variables, and evidence on the role of cognitive function in the relationship between age and health literacy was limited. In addition to these gaps, the distribution of health literacy skill decline in an older population has never been demonstrated. Demonstrating an independent relationship between age and health literacy, as well as identifying mediators of this relationship, would be important for researchers, health practitioners, and policymakers because low health literacy contributes to morbidity and mortality among older adults in England and globally (Bostock & Steptoe, 2012; Kickbusch et al., 2013).

During ageing, health literacy becomes increasingly important to maintain health, well-being, and independence. Previous evidence from the English Longitudinal Study of Ageing indicates that at least one-third of adults aged 52 years and over in England has limited health literacy, meaning that they get at least one out of four basic reading comprehension questions about a medicine label incorrect (Bostock & Steptoe, 2012). Over a six-year follow-up, those older adults who got one of four health literacy items incorrect had 15% increased odds of dying (adjusted OR=1.15; 95% CI: 0.94-1.41) and those who got at least two of four items incorrect had 40% increased odds of dying (adjusted OR=1.41; 95% CI: 1.15-1.72), compared to those who answered all four health literacy items correctly (Bostock & Steptoe, 2012). Given that about 15% of the adult population aged 16-64 years in England is functionally illiterate, and that literacy skills are often lower in adults aged ≥65 years than in younger adults, low functional health literacy in older English adults may be an important public health problem with implications for mortality risk (Harding et al., 2012). A better understanding of the distribution and dynamics of health literacy during ageing in England is needed.

[4] A version of this Chapter has been published in *J Gen Intern Med* (Appendix 8.1).

The aim of the analysis presented in this chapter was to address the limitations of previous cross-sectional studies and fill gaps in the literature by describing the nature of health literacy skill decline during ageing, identifying the sociodemographic factors associated with health literacy decline, and investigating the potential contributing roles of cognitive function and decline to ageing-related health literacy decline. I hypothesised that health literacy skills would show intra-individual decline over time during ageing, and that low cognitive function and ageing-related cognitive decline would be mediators of the relationship between increasing age and declining health literacy.[5] Data were from non-cognitively impaired English adults aged ≥52 years in the English Longitudinal Study of Ageing.

8.2 Methods

8.2.1 Sample

All ‘core’ ELSA participants from the original cohort who completed data collection at waves 2 (2004-5) and 5 (2010-11) without proxy interviews were eligible for inclusion. These two waves gave ‘baseline’ and ‘follow-up’ measures of health literacy performance, approximately six years apart. Wave 2 included 8780 core participants of the original 12,100. Of these, 5840 were in the study at wave 5 (33.5% attrition). After excluding the 224/5840 participants who had a proxy interview at either wave 2 or wave 5, the final eligible sample size was n=5616. The study eligibility flow is shown in Figure 8.1.

[5] A mediator is defined as any factor lying on the causal pathway between an exposure and outcome, which, in this case, are older age and declining health literacy, respectively.

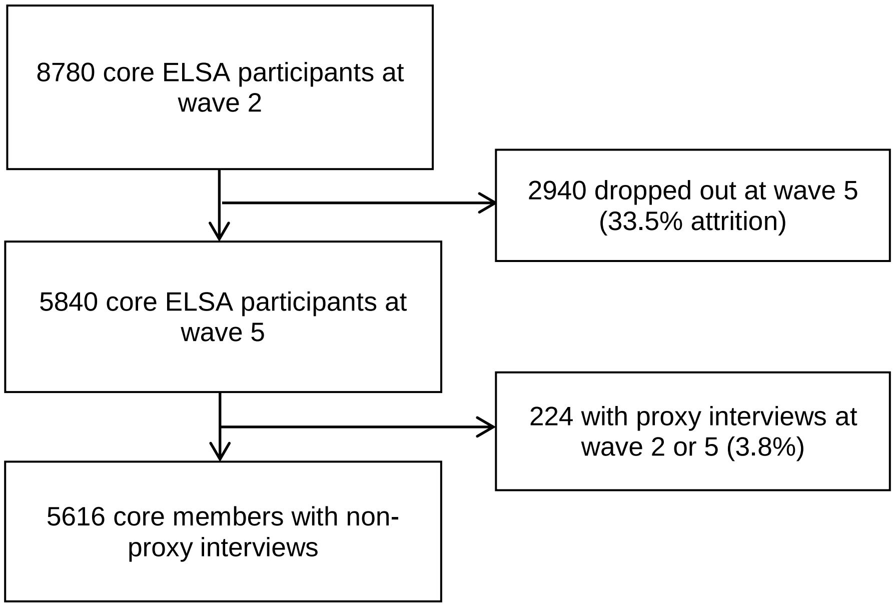

Figure 8.1 Study eligibility flow

8.2.2 Measures

8.2.2.1 Health literacy

Health literacy was assessed at waves 2 and 5 of the ELSA using a four-item measure from the IALLS, developed by the OECD and Statistics Canada (Thorn, 2009). The health literacy task was developed using a framework that defined literacy as a functional capability to fulfil goal-directed tasks, as reviewed in Chapter 1. Participants were asked to read a fictitious medicine label similar to that found on an aspirin packet, blown up to A4 size. The fictitious medicine label is shown again on the next page in Figure 8.2, and the interviewer instructions with the four reading comprehension questions that accompany the label are shown in Figure 8.3.

MEDCO TABLET

INDICATIONS: Headaches, muscle pains, rheumatic pains, toothaches, earaches.
RELIEVES COMMON COLD SYMPTOMS

DOSAGE: ORAL. 1 or 2 tablets every 6 hours, preferably accompanied by food, for not longer than 7 days. Store in a cool, dry place.

CAUTION: Do not use for gastritis or peptic ulcer. Do not use if taking anticoagulant drugs. Do not use for serious liver illness or bronchial asthma. If taken in large doses and for an extended period, may cause harm to kidneys. Before using this medication for chicken pox or influenza in children, consult with a doctor about Reyes Syndrome, a rare but serious illness. During lactation and pregnancy, consult with a doctor before using this product, especially in the last trimester of pregnancy. If symptoms persist, or in the case of an accidental overdose, consult a doctor. Keep out of reach of children.

INGREDIENTS: Each tablet contains
500 mg acetylsalicylic acid.
Excipent c.b.p 1 tablet
Reg. No. 88246

Made in Canada by STERLING PRODUCTS. INC
1600 Industrial Blvd. Montreal, Quebec H9J 3P1

Figure 8.2 The IALLS/ELSA health literacy measure

CFLITA @
SHOW CARD AQ
The final task in this section is about comprehension. Please turn to card AQ. This is a made-up medicine label and does not refer to a real medicine. It is often difficult to read and understand instructions on medicine labels. In a moment, I will ask you to read the card quietly to yourself. I will then ask you some questions about what it says. You do not have to memorise the card, as you will be able to look at it while answering the questions.
INTERVIEWER: Please give the respondents time to read the showcard.
If needed, confirm that they do not need to read the label out loud or memorise what it says.
Press one and <Enter> to continue.
Range: 1..1

CFLITSK
INTERVIEWER: Is the respondent able to do the literacy test?
1 Yes
2 No - sight difficulties
3 No - health problems
4 No - other (Specify)

IF whether able to do literacy test = No – Other reason [CfLitSK = 4]
|
| **CFLITSO @**
| INTERVIEWER: Record other reason.
| String 150
|
| ***[Open responses to Cflitso were coded and then incorporated into Cflitsk. Cflitc***
| ***identifies |that an open response was given at Cflitso and incorporated into Cflitsk]***
|
END OF FILTER

IF whether able to do literacy test = Yes [CfLitSK = 1]
|
| CFLITB
| Looking at the card, what is the maximum number of days you may take this medicine?
| INTERVIEWER: The correct response is 7. If responds with 'one week', probe for number of
| days. Code whether respondent gives correct or incorrect answer.
| 1 Correct answer: seven
| 2 Incorrect answer: any other response
|
| CFLITC
| Looking at the card, list three situations for which you should consult a doctor.
| INTERVIEWER: Respondent should mention at least three of the following. Stop when
| respondent mentions three:
| - (Before giving medication to children with) chicken pox
| - (Before giving medication to children with) influenza
| - Reyes syndrome
| - (During) lactation
| - (During) pregnancy,
| - If symptoms persist
| - (Accidental) overdose
| INTERVIEWER: Code whether respondent gives correct or incorrect answer.
| 1 Correct answer: at least three situations
| 2 Incorrect answer: any other response
|

(Figure continued on next page)

```
| CFLITD
| Looking at the card, list one condition for which you might take the Medco tablet.
| INTERVIEWER: Respondent should mention at least one of the following as conditions for
| which you could take the tablet:
| - Headaches
| - Muscle pains
| - Rheumatic pains
| - Toothache
| - Earache
| - Common cold
| INTERVIEWER: Code whether respondent gives correct or incorrect answer.
|  1 Correct answer: one correct condition
|  2 Incorrect answer: any other response
|
| CFLITE
| Looking at the card, list one condition for which you should not take the Medco tablet.
| INTERVIEWER: Respondent should mention at least one of the following as conditions for
| which you should not take the tablet:
| - Gastritis
| - Peptic ulcer
| - Serious liver illness
| - Bronchial asthma
| INTERVIEWER: Code whether respondent gives correct or incorrect answer.
|  1 Correct answer: one correct condition
|  2 Incorrect answer: any other response
|
END OF FILTER
```

Figure 8.3 Interviewer instructions for the ELSA health literacy measure

The reading comprehension questions represented what a person should be able to correctly answer to take the medication properly. This measure of health literacy assesses functional health literacy skills, and uses similar skills to the TOFHLA or the NVS. Adequate health literacy was defined as scoring 4/4 correct on the measure and limited health literacy as scoring <4/4 correct. Health literacy decline was defined as a decrease of ≥1 point in score between waves. Few participants declined by more than one point on the scale, so declines of greater magnitudes could not be investigated.

8.2.2.2 Cognitive function variables

The main in-person ELSA study interviews at waves 2 and 5 included an interviewer-administered cognitive battery, which assesses several cognitive processes that are essential to daily functioning and are sensitive to decline with ageing and measured in a way to prevent ceiling or floor effects (Banks et al., 2006). The cognitive processes assessed were:

Measures of memory:

- **Self-reported memory:** Participants were asked to rate their memory at the present time as excellent, very good, good, fair, or poor. They were also asked to rate whether their memory is now better, the same, or worse than two years ago. Because the responses to this variable were poorly associated with objectively-assessed memory, this variable was not included in this analysis (Banks et al., 2006).
- **Time orientation:** The ability to state the correct day, week, month, and year, which is a simple but effective test of memory. This item comes from the Mini-Mental State Examination (MMSE), a screening test for cognitive impairment. Participants were scored from zero to four items correct for time orientation.
- **Immediate recall and delayed recall:** Ten common words were presented aurally to participants by a standardised computerised voice with a two second gap between words. Participants were asked to verbally recall as many words as possible immediately and again after a delay filled with other cognitive tests. The test is scored as the number of words recalled out of ten for each of immediate and delayed recall.
- **Prospective memory:** In this test of memory for future actions (i.e. 'remembering to remember'), participants were instructed to remember to write their initials in the upper left-hand corner of a clipboard page at a certain point in the interview. If participants spontaneously recalled the task and wrote their initials at the appropriate point, they were scored as correct. This item is from the MRC Cognitive Function and Ageing Study (MRC CFA Study, 1998).

Measures of executive function:

- **Verbal fluency:** This test assesses how quickly participants can think of words from a particular category, in this case, naming as many animals as possible in one minute. The number of animals named is categorised into '0 animals', '1-7 animals', '8-12 animals', '13-15 animals', '16-17 animals', '18-19 animals', '20-21 animals', '22-24 animals', '25-29 animals', and '≥30 animals', to standardise the responses. The variable thus has a range of 0 to 9.
- **Mental processing speed:** The participant is given a clipboard with a page of random letters in a grid, and is asked to cross out as many target letters (P and W) as possible within one minute. The grid has 26 rows and 30 columns, and the participant is asked to work across and down the page as though he or she is reading, and to perform the task as quickly and as accurately as possible. The test is scored as the number of P's and W's crossed out. The test was

developed for use in the 1946 birth cohort study, and has been used in the MRC Cognitive Function and Ageing Study (MRC CFA Study, 1998; Richards, Kuh, Hardy, & Wadsworth, 1999).

The cognitive processes that were assessed in a way so that their measurements would be minimally affected by literacy skills were considered as potential determinants of health literacy: time orientation, immediate recall, delayed recall, and verbal fluency (Bostock & Steptoe, 2012). The prospective memory and mental processing speed tasks were not included as predictors of health literacy because they directly use reading and writing skills. The prospective memory test requires the participant to initial a certain page of the interview booklet at a specifically named time, and the prospective memory test requires the participant to search a grid of alphabet letters for two target letters (P and W) and cross them out.

The time orientation, immediate recall, and delayed recall tests were grouped together to create a memory index, with potential scores ranging from 0 to 24 (Steptoe, Demakakos, & de Oliveira, 2012). Scores on the verbal fluency test, which is an indicator of frontal lobe or executive function, ranged from 0 to 9 (Ruff, Light, Parker, & Levin, 1997). For the memory index, cognitive decline was defined as a decline of >1 point in score between waves 2 and 5 (Banks et al., 2006). Decline in memory performance is a sensitive indicator of clinically relevant cognitive decline leading to a state of pre-dementia (D. M. Jacobs et al., 1995). For the verbal fluency measure, decline was defined as decline of ≥1 point in score between waves 2 and 5. Each point corresponds to a difference of two or more animals named, which is considered to be a more clinically significant indicator of verbal fluency decline than the untransformed measure of one point per single animal named (Banks et al., 2006). Memory and verbal fluency will collectively be referred to as ‘cognitive function’, and decline in memory and verbal fluency as ‘cognitive decline’ throughout this chapter.

8.2.2.3 Sociodemographic covariates

Sociodemographic covariates obtained from the wave 2 interview were: age (52-54; 55-59; 60-64; 65-69; 70-74; 75-79; ≥80), sex (male; female), ethnicity (white; non-white), educational attainment (degree or equivalent; up to degree level; no qualification), net non-pension wealth in quintiles calculated stratified by age (<65 vs. ≥65) to account for the effect of retirement on wealth, and occupational class according to the three-category UK National Statistics Socioeconomic Classification (managerial; intermediate; routine). Age began at 52 rather than 50 years because this analysis begins two years into ELSA data collection at wave 2. Age was analysed categorically, because all ages over 89 years are collapsed into a single category to prevent identification of participants due to sparse observations in this age range. This categorisation of the age variable prevents continuous analysis of age in the ELSA when the full age range is used. In the present analysis, all ages over 79 years were collapsed to maintain an adequate sample size for the analyses, as few adults were over 89 years of age.

8.2.3 Statistical analysis

The prevalence of limited health literacy was calculated overall and by 5-year age group at baseline. Mean health literacy scores at each wave were calculated and graphed by five-year age group, and compared across age groups using the Kruskal-Wallis test and within age groups using the Wilcoxon sign-rank test for matched pairs. Logistic regression models adjusted for all sociodemographic variables and self-rated eyesight were used to estimate odds ratios (ORs) and associated 95% confidence intervals (CIs) for the associations between age, sociodemographics, and health literacy decline.

To prevent the baseline adjustment bias (Dugravot et al., 2009; Glymour, Weuve, Berkman, Kawachi, & Robins, 2005), baseline health literacy was not adjusted for in regression modelling. The baseline adjustment bias is a spurious association between the exposure and outcome that occurs when the baseline measure of the outcome variable is conditioned on, if the exposure predicts the baseline level of the outcome and especially if two other common conditions are met: 1) measures of the outcome variable fluctuate due to imperfect measurement (such as self-report), and 2) change in the outcome variable has already occurred prior to baseline, and the past rate of change predicts the future rate of change, and the exposure is unaffected by the baseline outcome variable (Glymour et al., 2005). In this instance, age (the exposure) and the wave 2 health literacy score (baseline measure of the outcome) were associated (Banks et al., 2006). Health literacy was measured imperfectly due to the nature of the 4-point scale, it can be assumed that past rate of change in health literacy predicts future rate of change, and age was unaffected by health literacy score. Hence, the baseline adjustment bias was deemed likely to occur if baseline health literacy was conditioned on in the multivariable model.

Baseline time orientation, memory, and verbal ability were added to the model to determine their independent associations with health literacy decline and their mediating effects on the association with age; memory decline and verbal ability decline were then added in a second step. A sensitivity analysis was performed, redefining cognitive decline variables according to increasingly conservative definitions of decline: decreases of >2 and >5 points on each index. A *post-hoc* analysis of diagnosis of chronic diseases that may affect cognition was run to assess their potential additional contribution to explaining the association between age and health literacy. Chronic diseases were cancer, diabetes, heart disease (angina, heart attack, abnormal heart rhythm, or congestive heart failure), chronic lung disease (chronic bronchitis or emphysema), and depressive symptoms. A second *post-hoc* analysis was conducted with prospective memory and mental processing speed measures included in the model, to examine the degree to which their adjustment may have changed the results for the association between age and health literacy. All analyses were conducted using StataSE 13.1 (StataCorp, College Station, TX).

8.3 Results

8.3.1 Missing data

Of the 8780 participants present at wave 2, 8316 (94.7%) completed the health literacy assessment. Common non-completion reasons were sight difficulties (n=132), health problems (n=59), or that the interview was done by proxy due to physical or cognitive impairment of the participant, and therefore was not eligible for the health literacy assessment (n=92). Of the 5840 core participants in the study at wave 5, 5330 (91.3%) completed the health literacy assessment. Common reasons for non-completion of the health literacy assessment at wave 5 were sight problems (n=96), health problems (n=37), and having a study interview done by proxy (n=214). In total, 5256/5840 participants had data on health literacy at both time points (90.0%).

Of these remaining 5256 participants, one was missing data on education, two on ethnicity, and four on occupational class, one on self-rated eyesight, one on memory at wave 2, one on verbal fluency at wave 2, and two on verbal fluency at wave 5 (not mutually exclusive). The univariate analysis of health literacy decline included all 5256 participants and the multivariable models included 5251 participants (age + sociodemographics and visual function), 5250 participants (age +

sociodemographics and visual function + baseline cognitive function), and 5249 participants (age + sociodemographics and visual function + baseline cognitive function + cognitive decline).

8.3.2 Sample characteristics

Characteristics of the sample are shown in Table 8.1. At baseline, 1455/5256 (27.7%) participants had limited health literacy. The most frequent age groups were in the 55 to 69 year range. Just over half of the sample was female (56%; 2960/5256). Only 2% were from a non-white ethnic background (85/5256). One-third of the sample was in the professional or managerial occupational class (34%; 1797/5256), while 26% were in the intermediate class (1364/5256), and 39% were in the routine or manual class (2040/5256). One-quarter of the sample had degree level education (24%; 1268/5256), 45% had up to degree level education (2349/5256), and nearly one-third had no educational qualification (31%; 1635/5256). The majority had excellent, very good, or good self-rated eyesight (90%; 4725/5256). The mean memory score, out of the sum of 24 (4 points for correct day, week, month, and year; 10 for immediate recall words; and 10 for delayed recall words) was 14.6 (SD 3.2). The mean number of animals named in one minute was 21.1 (SD 6.2). When the number of animals listed was categorised into a score from 0 to 9, the mean was 5.8 (SD 2.1), corresponding to 20-21 animals listed (Table 8.1).

Table 8.1 Baseline characteristics of participants, n=5256

Characteristic	N (%)
Age	
52-54	526 (10%)
55-59	1346 (26%)
60-64	995 (19%)
65-69	952 (18%)
70-74	692 (13%)
75-79	478 (9%)
≥80	267 (5%)
Health literacy	
Adequate	3801 (72%)
Limited	1455 (28%)
Sex	
Male	2296 (44%)
Female	2960 (56%)
Ethnicity	
White	5169 (98%)
Non-white	85 (2%)
Occupational class	
Managerial	1797 (34%)
Intermediate	1364 (26%)
Routine	2040 (39%)
Other	53 (1%)
Educational attainment	
Degree or equivalent	1268 (24%)
Up to degree level	2349 (45%)
No qualification	1635 (31%)
Self-rated eyesight	
Excellent/Very Good/Good	4725 (90%)
Fair/Poor/Registered as blind*	530 (10%)
Memory index (out of 24)	
Mean (SD)	14.6 (3.2)
Median	15
Range	2-24
Verbal fluency (untransformed)	
Mean (SD) number of animals listed	21.1 (6.2)
Median	21
Range	0-63
Verbal fluency (categorical)	
0 animals (category 0)	2 (0%)
1-7 animals	47 (1%)
8-12 animals	263 (5%)
13-15 animals	588 (11%)
16-17 animals	610 (12%)
18-19 animals	700 (13%)
20-21 animals	711 (14%)
22-24 animals	949 (18%)
25-29 animals	933 (18%)
≥30 animals (category 9)	453 (9%)
Verbal fluency (transformed for analysis)	
Mean (SD) category of animals listed	5.8
Median	2.1
Range	0-9

*Few participants reported being registered as blind (3/5256)

8.3.3 Univariate analysis of health literacy decline

When followed forward to wave 5, 3260/5256 participants (62.0%) had no change in their health literacy score, while 964/5256 (18.3%) improved by ≥1 point and 1032/5256 (19.6%) declined by ≥1 point. Chi-squared tests showed that improvement in score was non-differential by age (p=0.53), while decline was more frequent in older age groups (p<0.001). The proportion that declined increased linearly with age from 14.8% (78/526) of those aged 52-54 (102/267) to 38.2% of those aged ≥80 years (p<0.0001). Mean health literacy scores declined over the study follow-up for age groups 65-69 years and older; this decline was statistically significant for the 75-79 (p=0.008) and ≥80 (p<0.001) groups (Figure 8.4).

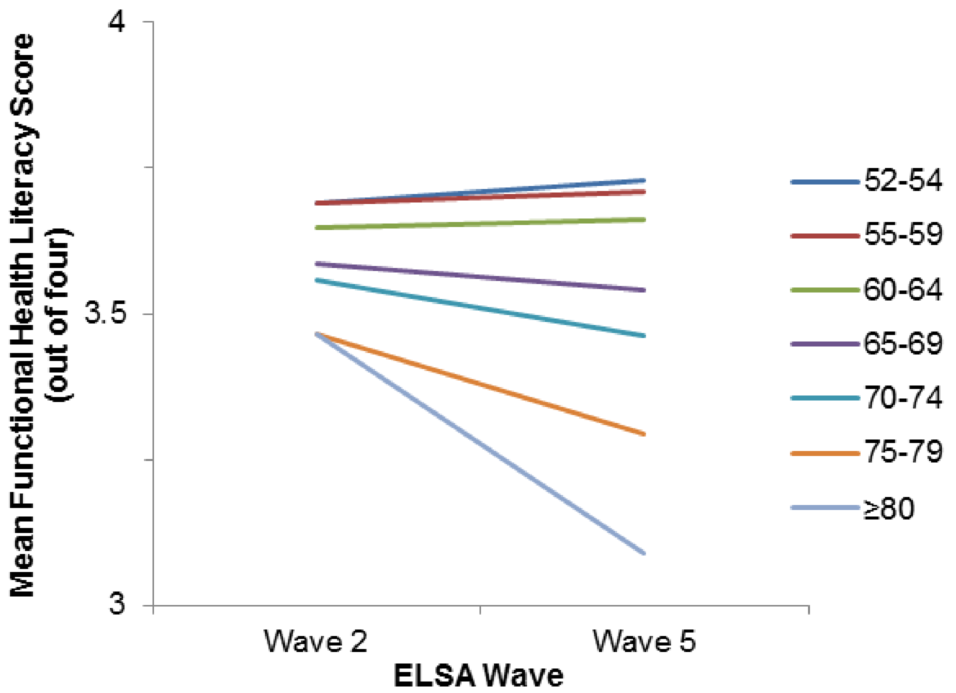

Figure 8.4 Mean health literacy scores in waves 2 and 5 by age group

8.3.4 Multivariable modelling of health literacy decline

Table 8.2 shows the results for the multivariable logistic regression model adjusted for sex, ethnicity, occupational class, educational attainment, and self-rated eyesight. Net non-pension wealth was ultimately not included in the model as it was not an independent predictor of health literacy decline and it had a high degree of missing observations (>5%). The inclusion of this variable was judged to not justify the volume of missing data it would introduce. In this adjusted model, the OR for health literacy decline among those aged 65-69 years vs. 52-54 years was 1.35 (95% CI: 1.01–1.82; Table 8.2). ORs increased in a linear fashion across age groups up to 3.13 (95% CI: 2.20–4.46) for the ≥80 vs. 52-54 years age group (p_{trend}<0.001). Independently of baseline age, the sociodemographic risk factors for health literacy decline were: being male (OR=1.22; 95% CI: 1.05–1.40), of a non-white ethnicity (OR=2.30; 95% CI: 1.43–3.71), being in an occupational class lower than professional/managerial (OR=1.34; 95% CI: 1.10–1.63 for intermediate and OR=1.64; 95% CI: 1.36–1.97 for routine), and having no educational qualifications (OR=1.56; 95% CI: 1.27–1.93). Having Fair/Poor self-rated eyesight or being registered as blind was a risk factor for health literacy decline (OR=1.44; 95% CI: 1.17-1.78 vs. Excellent/Very Good/Good).

Table 8.2 Multivariable-adjusted associations between age, sociodemographic factors, cognition, and health literacy decline, n=5256

Characteristic	Odds ratios for health literacy decline		
	Model 1 OR* (95% CI)	Model 2 OR† (95% CI)	Model 3 OR‡ (95% CI)
Age			
52-54	1.00 (ref)	1.00 (ref)	1.00 (ref)
55-59	0.92 (0.69, 1.23)	0.89 (0.66, 1.18)	0.87 (0.65, 1.16)
60-64	1.08 (0.80, 1.45)	0.97 (0.72, 1.31)	0.92 (0.68, 1.24)
65-69	1.35 (1.01, 1.80)	1.18 (0.88, 1.58)	1.07 (0.79, 1.44)
70-74	1.52 (1.12, 2.05)	1.24 (0.91, 1.69)	1.07 (0.78, 1.46)
75-79	1.92 (1.40, 2.64)	1.47 (1.06, 2.05)	1.17 (0.84, 1.64)
≥80	3.13 (2.20, 4.46)	2.21 (1.53, 3.18)	1.68 (1.15, 2.44)
Sex			
Female	1.00 (ref)	1.00 (ref)	1.00 (ref)
Male	1.22 (1.05, 1.40)	1.17 (1.01, 1.35)	1.14 (0.98, 1.32)
Ethnicity			
White	1.00 (ref)	1.00 (ref)	1.00 (ref)
Non-white	2.30 (1.43, 3.71)	1.73 (1.07, 2.81)	1.58 (0.97, 2.57)
Occupational class			
Managerial	1.00 (ref)	1.00 (ref)	1.00 (ref)
Intermediate	1.34 (1.10, 1.63)	1.27 (1.04, 1.56)	1.27 (1.04, 1.55)
Routine	1.64 (1.36, 1.97)	1.47 (1.21, 1.77)	1.41 (1.16, 1.71)
Other	1.81 (0.97, 3.36)	1.55 (0.83, 2.90)	1.46 (0.77, 2.73)
Educational attainment			
Degree or equivalent	1.00 (ref)	1.00 (ref)	1.00 (ref)
Up to degree level	1.03 (0.85, 1.25)	1.02 (0.84, 1.24)	1.03 (0.85, 1.26)
No qualification	1.56 (1.27, 1.93)	1.35 (1.10, 1.67)	1.31 (1.06, 1.62)
Self-rated eyesight			
Ex./Very good/Good	1.00 (ref)	1.00 (ref)	1.00 (ref)
Fair/Poor/Blind	1.44 (1.17, 1.78)	1.40 (1.13, 1.73)	1.36 (1.10, 1.68)
Baseline memory			
Per 1-point increase	–	0.95 (0.92, 0.97)	0.92 (0.90, 0.95)
Baseline verbal fluency			
Per 1-point increase	–	0.90 (0.87, 0.94)	0.88 (0.85, 0.92)
Memory decline			
No			1.00 (ref)
Yes	–	–	1.60 (1.36, 1.87)
Verbal fluency decline			
No			1.00 (ref)
Yes	–	–	1.46 (1.25, 1.71)

*Adjusted for age, sex, ethnicity, occupational class, educational attainment, and self-rated eyesight; n=5251
†Model 1 + baseline memory and verbal fluency; n=5250
‡Model 2 + memory and verbal fluency decline; n=5249

Mean baseline memory and verbal fluency decreased with age (p<0.0001). Higher baseline cognitive function was protective against health literacy decline regardless of age, where every 1-point increase in memory score was associated with an OR of 0.95 (95% CI: 0.92–0.97) and every 1-point increase in verbal fluency score was associated with an OR of 0.90 (95% CI: 0.87–0.94) for health literacy decline (Table 8.2). The likelihood of cognitive decline over the follow-up period increased with age: 29.7% (156/525) of those aged 52-54 experienced memory decline, compared with 52.1% (141/267) of those aged ≥80; the corresponding values for verbal fluency decline were 36.2% (190/525) and 52.4% (140/267) (p<0.001 for both). As shown in Table 8.2, memory decline and verbal fluency decline were associated with health literacy decline independently of age (OR=1.60; 95% CI: 1.36–1.87 and OR=1.46; 95% CI: 1.25–1.71). Baseline cognitive function and cognitive decline over the follow-up period explained most of the association between health literacy decline and age. Among those aged ≥80 years, there was a residual degree of health literacy decline that was not explained by the variables in the final model (OR=1.68; 95% CI: 1.15–2.44 for ≥80 vs. 52-54 years).

The associations between sociodemographic variables and health literacy decline mostly persisted regardless of adjustment for cognitive function and cognitive decline (Table 8.2). However, the remaining association between sex and health literacy decline was of weak magnitude, and was attenuated to borderline statistical significance after accounting for cognitive variables. Men, in fact, had slightly lower mean baseline memory scores than women (14.2 SD 3.1 vs. 14.9 SD 3.2; p<0.0001), but higher mean baseline verbal fluency scores than women (6.0 SD 2.0 vs. 5.7 SD 2.1; p<0.0001). Memory decline and verbal fluency decline did not differ by sex, indicating that cognitive decline does not explain sex differences in health literacy decline. The association between ethnicity and health literacy decline was of weak magnitude and imprecise due to the small number of non-white adults in the sample, which may be partly why adjustment for cognitive measures attenuated the association. Ethnic minority adults had lower mean baseline memory scores than white adults (13.3 SD 3.4 vs. 14.6 SD 3.2; p<0.0001), as well as lower mean baseline verbal fluency scores (4.1 SD 2.1 vs. 5.9 SD 2.1; p<0.0001). Memory decline and verbal fluency decline did not differ by ethnicity, indicating that cognitive decline also does not explain ethnic differences in health literacy decline.

8.3.5 Sensitivity and *post-hoc* analyses

When memory decline was defined as declines of >2 and >5 points, 1369/5255 (26.1%) and 353/5255 (6.7%) participants were defined as experiencing memory decline. The corresponding values for these re-definitions of verbal fluency decline were 577/5254 (11.0%) and 35/5254 (<1.0%). When the decline variables defined as >2 points decline were added to the final model, the associations between cognitive decline and health literacy decline became slightly stronger in magnitude (OR=1.64; 95% CI: 1.39–1.94 for memory decline and OR=1.52; 95% CI: 1.22–1.90 for verbal fluency decline). When the decline variables defined as >5 points decline were added to the final model, the association between memory decline and health literacy decline became even stronger (OR=1.86; 95% CI: 1.44–2.41), although the association between verbal fluency decline and health literacy decline was null (OR=1.14; 95% CI: 0.50–2.62). This estimate is imprecise because less than 1% of participants declined by >5 points in verbal fluency. Having a chronic disease diagnosis or depressive symptoms were not associated with health literacy decline and did not affect the ORs for any of the other variables and health literacy decline when added to the final model (not shown). Addition of prospective memory and mental processing speed scores to the cognitive function indices in the model also did not affect any ORs for the other variables and health literacy decline (not shown; see Appendix 8.1 for the results of the published journal article, which are adjusted for prospective memory and mental processing speed).

8.4 Discussion

Consistent with previous research using the same dataset, nearly one third of adults aged 52 years and over had health literacy limitations at wave 2 in the English Longitudinal Study of Ageing (Bostock & Steptoe, 2012). Over the six-year follow-up period, about one-fifth of the sample declined in health literacy skills. Age differences in the likelihood and rate of health literacy decline were pronounced, with adults aged 80 years and over having more than three times greater odds of experiencing health literacy decline than those in their early 50s. Striking social inequalities in health literacy decline were evident, where men and adults from deprived social backgrounds were the most vulnerable to lose the literacy skills required to manage health during ageing. Cognition appears to be a key risk factor explaining health literacy decline. Even subtle, one-point differences in cognitive function affected the likelihood of health literacy decline, and experiencing cognitive decline of any magnitude was strongly associated with health literacy decline.

My finding that cognitive function mostly explained the relationship between older age and health literacy decline was expected based on cross-sectional evidence showing that the constructs of cognition and health literacy overlap to a large degree (Kaphingst, Goodman, Macmillan, Carpenter, & Griffey, 2014; Levinthal et al., 2008; Mõttus et al., 2014; Wolf et al., 2012). Contrary to my findings, three other studies found that the association between age and health literacy was independent of cognitive impairment according to the Mini Mental Status Examination (MMSE) (Armistead-Jehle et al., 2010; D. W. Baker et al., 2002; Gazmararian et al., 1999). However, the MMSE does not detect subtle individual differences in cognitive function, as this study did. An important aspect of this study is that not everyone who experienced cognitive decline also experienced health literacy decline. The degree to which typical cognitive ageing versus ageing-related cognitive impairments of varying severities affect health literacy skills remains to be elucidated. This study suggests that non-pathological cognitive decline negatively affects health literacy during ageing. Further longitudinal studies that address the fluidity of literacy and cognition during ageing are needed for consideration alongside this study.

8.4.1 Limitations

Although validation data for the individual health literacy measure I used were not available, it was taken from a validated international adult literacy survey (Thorn, 2009). The measure does not capture prose literacy, information navigation, or numeracy, although it is a measure of document literacy that has good face validity. The ability to read and understand a medicine label is crucial to several health outcomes, and has been associated with risk of all-cause mortality among older English adults (Bostock & Steptoe, 2012). The scale had narrow range and a ceiling effect, where over two-thirds of the study sample scored 4/4 on the scale at both time points; this is a common problem in health literacy measures (Davis et al., 1993; Parker et al., 1995). Consequently, few participants declined by more than 1 point on the health literacy measure (316/5256; 6%), preventing me from examining decline of varying magnitudes and from varying starting points. The distribution of change scores among those who declined was: -1 point (716/5256; 14%), -2 points (238/5256; 5%), -3 points (64/5256; 1%), and -4 points (14/5256; <1%). I could not examine non-linear change or change over a period longer than the six-year follow-up. If further follow-up data on health literacy are collected in future waves of the ELSA, this would be an important area for future research.

I observed a degree of health literacy decline among adults aged ≥80 years that was not explained by cognitive variables, which might be because the ELSA dataset does not account for all aspects of cognitive function. For example, inductive reasoning was not measured, but is correlated with both age and health literacy (A Singh-Manoux et al., 2012; Wolf et al., 2012). I also had no measures of the component processes involved with active learning including knowledge integration and text inference, which predict reading comprehension skills among older adults (Hannon & Daneman, 2009). However, the aspects of short-term memory and verbal fluency that were measured are related to these abilities and were taken from established and validated measures that are used in other longitudinal studies of ageing. This research should therefore be interpreted jointly with other studies that have a greater range of cognitive function measures.

Another important limitation of this study is attrition bias. The prevalence of limited health literacy at baseline was 42% among those who dropped out of the study, but was only 28% among those who remained in the study between waves. Study attrition also increased with age, from approximately 26% among those aged 52-54 years to 71% among those aged ≥80 years. My results may therefore underestimate the true prevalence of limited health literacy among the older English population, particularly in the most elderly age group. Ethnic minorities, participants with no educational qualifications, and those with routine occupations were more also likely to drop out of the study, and were more likely to have limited health literacy at baseline. I may have underestimated the magnitude of associations between these sociodemographic variables and health literacy decline.

8.4.2 Strengths

To the best of my knowledge, this longitudinal study is the first to track health literacy skills over time, particularly among an ageing sample. The large sample size and rich data on sociodemographic and cognitive factors alongside data on fluid health literacy skills in the ELSA made this analysis possible. In addition to adjusting for sociodemographic and cognitive factors, I also accounted for self-reported eyesight. I did this based on the suggestion of a letter to the editor of *J Gen Intern Med* following the original publication of this study (Matthiesen, Vela, & Press, 2015). It is important to account for this variable because functional health literacy performance partly depends on one's visual function. The health literacy measure used in the ELSA has good face validity and predictive capability for mortality risk, and was taken from a validated international adult literacy survey. The cognitive function variables that were assessed as predictors of health literacy were those known to be sensitive to change with age that would be minimally affected by literacy skills. As a longitudinal analysis conducted with little prior knowledge on health literacy during ageing, this study provides valuable evidence for future research hypotheses.

8.4.3 Conclusions

The literacy skills required to manage health appear to undergo ageing-related decline among older English adults beginning, on average, around age 65. Rate of decline increases with age, with adults aged ≥80 years being vulnerable to rapid health literacy decline. Health literacy decline among older adults is marked by social inequalities, whereby men and adults from deprived social backgrounds were the most vulnerable to skill loss during ageing. Cognitive function and even slight cognitive decline during ageing appeared to affect the likelihood of health literacy decline, particularly among the older age groups in the sample. Finally, given that literacy skills are commonly lost during ageing, a time when adults often need health information and services, the current population-wide burden of low health literacy may be substantial. Whether health literacy decline may be prevented through potentially modifiable behavioural influences on health literacy is unknown. For example, Internet use and mentally stimulating social activities may help adults to maintain or improve health literacy through directly stimulating cognitive and literacy skills. These relationships, which have never been investigated longitudinally, will be the focus of the next chapter.

Chapter 9. Study 3: Internet use, social engagement, and maintaining health literacy during ageing[6]

9.1 Background

The first two empirical studies of this dissertation showed that fluid functional health literacy skills decline during ageing in older English adults beginning, on average, around age 65. The systematic review and meta-analysis in Chapter 6 indicated that health literacy skills involving fluid cognitive functions were the most likely to decline during ageing (i.e. health literacy as measured by the TOFHLA, S-TOFHLA, and NVS). The longitudinal analysis in Chapter 8 then demonstrated that about one-fifth of older adults decline in score on a four-point functional health literacy scale over a six-year period, which is mostly explained by ageing-related decline in memory and verbal fluency. The next question I had was whether any modifiable behavioural practices might influence ageing-related health literacy decline, either independently of cognitive function and decline or not. This chapter therefore focuses on Internet use and social engagement as predictors of health literacy decline in the English Longitudinal Study of Ageing.

I selected Internet use and social engagement as predictor variables for investigation, due to their consistent and positive relationships with the maintenance of cognitive function during ageing in longitudinal studies. In the ELSA, Internet use has been positively associated with the maintenance of cognitive function over time during ageing (Xavier et al., 2014). As well, cross-sectional studies have shown that adults with lower health literacy are less likely to use the Internet than those with adequate health literacy (Echt & Burridge, 2011; Wister, Malloy-Weir, Rootman, & Desjardins, 2010). A systematic review of randomised, theory-based, online eHealth interventions to improve health literacy found that these types of digital interventions improve the performance of adults diverse by age and culture on health literacy assessments (R. J. Jacobs, Lou, Ownby, & Caballero, 2014). Whether this finding is a direct effect of technological learning on literacy is unclear; improved cognitive function may mediate this relationship (Tun & Lachman, 2010). The trained use of tablet computers, involving the use of the Internet in practical applications, has been shown to improve scores on measures of mental processing speed and immediate and delayed verbal recall over social and non-intellectually stimulating activities among 93 older American adults randomised into three arms (tablet computer

[6] A version of this Chapter has been published in *J Epidemiol Community Health* (Appendix 9.1).

intervention; social activities; non-intellectually stimulating activities) in a 1:1:1 ratio with matching on sociodemographic factors (Chan, Haber, Drew, & Park, 2014). However, measures of mental control (the ability to suppress or inhibit attention to a key feature of a presented stimulus) and visuospatial processing (identifying missing areas of a patterned image) were not affected by the use of tablet computers in this trial (Chan et al., 2014).

A range of social activities including physical activity[7], intellectual game-playing, membership in religious and other social groups, and participation in cultural activities have been positively associated with several measures of cognitive functioning in long-term longitudinal studies of older adults (Bassuk, Glass, & Berkman, 1999; Giles et al., 2012; Kraft, 2012; Mitchell et al., 2012; Thomas, 2011a; Wang et al., 2013). However, in a brief three-month randomised trial of socially and cognitively stimulating activities among 221 participants aged 60 to 90 years, immediate and delayed recall were not improved in a ‘social engagement’ arm of the trial (passive activities such as field trips that were novel but did not involve active learning), whereas it was in a ‘receptive engagement’ arm (active learning of novel skills) (Park et al., 2014). Evidently, this body of knowledge is still evolving, although it appears that cognitively stimulating social activities may help to maintain cognitive function, in particular immediate and delayed recall, during ageing. This relationship may extend to health literacy, acting via cognitive function or through directly improving literacy skills.

The aim of the present analysis was to investigate the roles of regular Internet use and social engagement (in civic, leisure, and cultural activities) in promoting the maintenance of health literacy during ageing (i.e. either no change or an improvement in health literacy score over time) among adults aged 52 years and over in the English Longitudinal Study of Ageing. Civic, leisure, and cultural activities were included, because each of these domains include intellectually stimulating social activities, in line with the evidence from longitudinal studies reviewed above. I hypothesised that Internet use and intellectually stimulating social activities would have positive effects on the maintenance of health literacy skills during ageing, and that these relationships may be explained by the positive effect of these factors on cognitive function or decline.

[7] The relationship between physical activity and health literacy, including the potential role of cognitive function in this relationship, will be a focus of Chapter 11, and will not be elaborated upon within the present Chapter.

9.2 Methods

9.2.1 Sample

All ‘core’ ELSA participants from the original cohort who completed data collection at all of waves 2 (2004/05), 3 (2006/07), 4 (2008/09), and 5 (2010/11) with non-proxy interviews were eligible for inclusion in this analysis. This study uses data from all of waves 2 through 5, as it focuses on consistent engagement in Internet use and social activities over time. Of the 8780 core participants who were in the study at wave 2, 5262 remained in the study at all waves through wave 5 (40.1% attrition). Of these, 20/5262 had a proxy interview at wave 2, 33/5262 had a proxy interview at wave 3, 62/5262 had a proxy interview at wave 4, and 109/5262 had a proxy interview at wave 5. After excluding all proxy interviews, the final eligible sample size was n=5125. The study eligibility flow is shown in Figure 9.1.

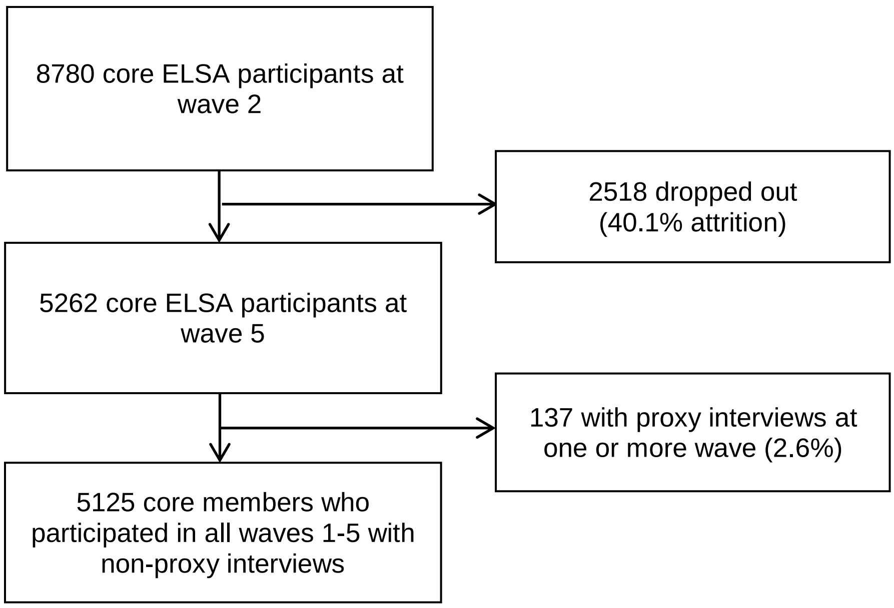

Figure 9.1 Study eligibility flow

9.2.2 Study measures

9.2.2.1 Health literacy

As in Chapter 8, health literacy was assessed using a four-item measure from the IALLS developed by the OECD and Statistics Canada (Thorn, 2009). Health literacy was measured at waves 2 (‘baseline’) and 5 (‘follow-up’) of ELSA during the in-person study interview. As in Chapter 8, health literacy decline was defined as decreasing in score by ≥1 point on the health literacy measure between waves 2 and 5.

9.2.2.2 Internet use

Data on Internet use were collected in a self-completion questionnaire that ELSA participants completed in addition to the in-person interview. Internet use was assessed at each wave using a checklist item, '*I use the internet and/or email*'. 'Never users' were those who did not tick the item in any wave, 'Intermittent users' inconsistently ticked the item across waves 2 to 5, and 'Consistent users' ticked the item in all waves.

9.2.2.3 Social engagement

Social engagement is conceptualised in this analysis using an index of 'social detachment' from the ELSA. The index includes a range of civic, leisure, and cultural activities that would use diverse cognitive functions including those involved in active learning (Table 9.1). A crude social network measure (i.e. having friends, children, or other immediate family and being in contact with them at least once per week) was originally included in the index but not used in the present study, due to the low variability in response to the variable and a lack of empirical evidence for the association between this variable and cognitive stimulation. Data were collected in the self-completion questionnaire, where participants ticked off the statements relating to them in each wave. Participants were categorised as being engaged or not engaged in each domain at each wave. Across all waves, social engagement was described as being 'Consistent', Intermittent', or 'None' for each domain.

Table 9.1 Civic, leisure, and cultural activities in the ELSA

Civic activities	Current member of a: - political party; or, - trade union or environmental group; or, - tenants' or neighbourhood group or neighbourhood watch; or, - church or religious group; or, - charitable association; And did volunteer work in the past year
Leisure activities	Current membership in a: - social club; or, - sports club; or, - gym or exercise class; or, - other organisation, club, or society
Cultural activities	In the past year, attending a: - cinema; or, - art gallery or museum; or, - theatre, concert, or opera performance

9.2.2.4 Covariates

Sociodemographic and health-related covariates considered as potential confounders were: age at wave 2 of data collection (52-54; 55-59; 60-64; 65-69; 70-74; 75-79; ≥80), sex, ethnicity (white; non-white), educational attainment (degree or equivalent; up to degree level; no qualification), occupational class according to the three-category UK National Statistics Socioeconomic Classification (managerial; intermediate; routine), net non-pension wealth quintile (stratified at age 65 to account for retirement), self-rated eyesight (Excellent/Very Good/Good; Fair/Poor/Registered as Blind), having a limiting long-standing illness (yes; no), and experiencing a limitation in any instrumental activity of daily living (IADL) over the follow-up period (yes; no). The cognitive covariates were the same as in Chapter 8: baseline memory (score out of 24 on the memory index, consisting of time orientation, and immediate and delayed recall), baseline verbal fluency (score out of 9 for number of animal names listed), memory decline (yes or no for decline of >1 point on the index between waves 2 and 5), and verbal fluency decline (yes or no for decline of ≥1 point on the index between waves 2 and 5).

9.2.3 Statistical analysis

The characteristics of the sample were described using means and standard deviations for continuous variables and frequency counts for categorical variables. Internet use and engagement in each of civic activities, leisure activities, and cultural activities at each wave were analysed bivariately against health literacy decline (yes vs. no) using the chi-squared test and were visualised as bar graphs. Multivariable logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (CIs) for the associations between Internet use and engagement in each of civic, leisure, and cultural activities (four main effects) and health literacy decline over the six-year follow-up. Three model sets were run: model set 1 was for the associations between each main effect and health literacy decline, adjusted for sociodemographic and health-related covariates; model 2 adjusted for all main effects simultaneously in addition to covariates; model 3 additionally included baseline cognitive function and cognitive decline variables to investigate their potential mediating effects on the relationships. A secondary analysis investigated the additive effect of maintaining engagement in one, two, three, or all four of internet use and civic, leisure, and cultural activities over the follow-up. A sensitivity analysis included measures of prospective memory and mental processing speed in the cognitive function indices that were adjusted for in the final model. To avoid the baseline adjustment bias, baseline health literacy was not adjusted for (Dugravot et al., 2009; Glymour et al., 2005). All regression models were population-weighted to account for study non-response and drop-out. All analyses were conducted using StataSE 13.1 (StataCorp, College Station, TX).

9.3 Results

9.3.1 Missing data

Of the 5125 eligible participants, 5017 (97.8%) completed the health literacy assessment at wave 2. Reasons for non-completion were sight difficulties (n=35), health problems (n=9), refusal (n=7), or another non-codeable reason (n=57). At wave 5, 4880/5125 (95.2%) eligible participants completed the health literacy assessment. Reasons for non-completion were sight difficulties (n=84), reading problems (n=25), health problems (n=31), refusal (n=41), confusion about what to do (n=14), or another reason such as anxiety, mental impairment, or interruption (n=50). In total, 4834/5125 (94.3%) participants had complete health literacy data.

The other main source of missing data was the self-completion questionnaire. Of the total eligible participants, 334/5125 (6.5%) did not return the self-completion questionnaire at wave 2, 430/5125 (8.4%) did not return it at wave 3, 444/5125 (8.7%) did not return it at wave 4, and 333/5125 (6.5%) did not return it at wave 5. When all waves were taken together, 1001/5125 (19.5%) did not return the self-completion questionnaire at one or more wave, meaning that data on Internet use and social engagement were missing from these participants. Other missing data were on ethnicity (2/5125; <1%), educational attainment (2/5125; <1%), self-rated eyesight (2/5125; <1%), baseline memory (15/5125; <1%), baseline verbal fluency (11/5125; <1%), memory decline (38/5125; <1%), and verbal fluency decline (37/5125; <1%). After all missing data were taken into account, 4002/5125 (78.1%) eligible participants were included in this analysis.

9.3.2 Sample characteristics

Characteristics of the participants are shown in Table 9.2. At baseline, 2942/4002 participants (74%) had adequate health literacy (Table 9.2). Over the six-year follow-up, 736/4002 participants (18%) declined by one or more point in health literacy score, while 705/4002 (18%) improved by one or more point. Despite the higher degree of missing data in this analysis, these proportions are consistent with those observed in Chapter 8. The proportion of adults with adequate health literacy was slightly higher than in Chapter 8, however, at 74% (2942/4002). Also as in Chapter 8, the proportion of adults who declined in health literacy score increased with age (*p*<0.0001), while improvement was non-differential by age (*p*=0.46).

Table 9.2 Characteristics of participants, n=4002

Characteristic	N (%)
Health literacy	
Adequate	2942 (74%)
Limited	1060 (26%)
Health literacy decline	
No	3266 (82%)
Yes	736 (18%)
Age	
52-54	388 (10%)
55-59	1000 (25%)
60-64	792 (20%)
65-69	742 (19%)
70-74	532 (13%)
75-79	357 (9%)
≥80	191 (5%)
Sex	
Male	1745 (44%)
Female	2257 (56%)
Ethnicity	
White	3969 (99%)
Non-white	33 (1%)
Educational attainment	
Degree or equivalent	1003 (25%)
Up to degree level	1834 (46%)
No qualification	1165 (29%)
Occupational class	
Managerial or professional	1394 (35%)
Intermediate	1048 (26%)
Routine	1530 (38%)
Other	30 (1%)
Limiting long-standing illness	
No	1862 (47%)
Yes	2140 (53%)
IADL limitation over the follow-up	
No	2906 (73%)
Yes	1096 (27%)
Self-rated eyesight	
Excellent/Very Good/Good	3637 (91%)
Fair/Poor/Registered as blind	365 (9%)
Memory index (out of 24)	
Mean (SD)	14.7 (3.2)
Median	15
Range	2-24
Verbal fluency (out of 9)	
Mean (SD)	5.9 (2.0)
Median	6
Range	0-9
Memory decline	
No	2608 (65%)
Yes	1394 (35%)
Verbal fluency decline	
No	2375 (59%)
Yes	1627 (41%)

Across the data collection waves, 1547/4002 participants (39%) reported never using the Internet or email, while 1469/4002 (37%) consistently reported use. Across waves, 1524/4002 participants (38%) were consistently engaged in civic activities, 1449/4002 (36%) in leisure activities, and 1821/4002 (46%) in cultural activities. Participation across civic, leisure, and cultural activities was significantly, but modestly correlated with Spearman's rho ranging from 0.30 to 0.33 (p<0.0001 for all). Among those who experienced health literacy decline, Internet use and engagement in all three social domains were lower at each wave than those who did not decline in health literacy (Figure 9.2).

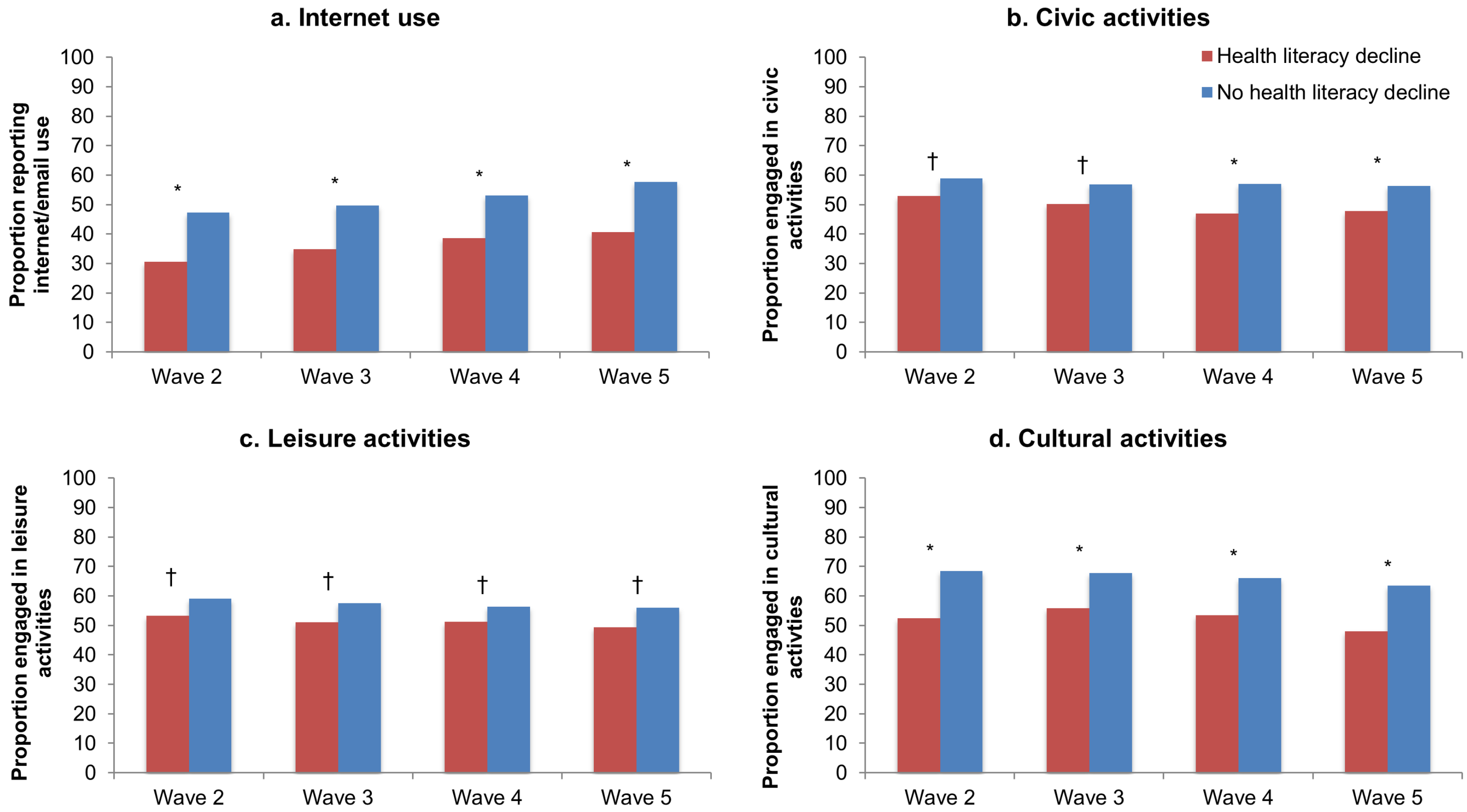

Figure 9.2 Internet use and social engagement according to health literacy decline, across waves $^{*}p$<0.0001; $^{\dagger}p$<0.01

9.3.3 Multivariable modelling of health literacy decline

In population-weighted multivariable logistic regression models adjusted for sociodemographic and health-related covariates, consistent Internet use was protectively associated with health literacy decline (OR=0.62; 95% CI: 0.48–0.80 vs. never use), as were consistent engagement in civic activities (OR=0.77; 95% CI: 0.61–0.97 vs. never engagement) and cultural activities (OR=0.59; 95% CI: 0.46–0.76 vs. never engagement; Table 9.3). Leisure activities were not significantly associated with health literacy decline. When all four main effects were mutually adjusted for in the same model, the association with civic activities was attenuated to the null. When the cognitive variables were entered into the model, the associations with Internet use and cultural engagement were somewhat attenuated, but remained statistically significant (OR=0.77; 95% CI: 0.59–0.99 for consistent Internet use and OR=0.70; 95% CI: 0.54–0.91 for consistent cultural engagement; Table 9.3).

Table 9.4 shows the additive effects of consistently engaging in multiple activities. When the number of activities was entered into the model as a linear variable (from 0 to 4), the OR for health literacy decline associated with each additional activity engaged in was 0.87 (95% CI: 0.80–0.95). The number of activities was then examined as a categorical variable. The OR for consistently engaging in any one of Internet use, civic, leisure, or cultural activities versus no engagement was 0.88 (95% CI: 0.71–1.10), compared with 0.78 (95% CI: 0.60–1.01) for engaging in any two, 0.68 (95% CI: 0.50–0.93) for engaging in any three, and 0.53 (95% CI: 0.34–0.83) for engaging in all four, a significant linear trend (p_{trend}<0.0001; Table 9.4).

9.3.4 Sensitivity analysis

When measures of prospective memory and mental processing speed were included in the cognitive function indices that were adjusted for in statistical modelling, results did not change (not shown; see Appendix 9.1 for the published results, which are adjusted for prospective memory and mental processing speed).

Table 9.3 Population-weighted, adjusted associations between internet use, social engagement, and health literacy decline, n=4002

	Health literacy decline							
Activities	Yes (n=736; 18%)	No (n=3266; 82%)	Model 1*	95% CI	Model 2†	95% CI	Model 3‡	95% CI
Internet use								
Never	378 (24%)	1169 (76%)	1.00	(ref)	1.00	(ref)	1.00	(ref)
Intermittent	182 (18%)	804 (82%)	0.88	(0.70, 1.10)	0.90	(0.72, 1.13)	0.95	(0.76, 1.19)
Consistent	176 (12%)	1293 (88%)	0.62	(0.48, 0.80)	0.68	(0.53, 0.88)	0.77	(0.59, 0.99)
Civic activities								
None	288 (23%)	777 (77%)	1.00	(ref)	1.00	(ref)	1.00	(ref)
Intermittent	273 (19%)	1200 (81%)	0.85	(0.68, 1.04)	0.89	(0.72, 1.11)	0.89	(0.71, 1.10)
Consistent	235 (15%)	1289 (85%)	0.77	(0.61, 0.97)	0.88	(0.69, 1.12)	0.90	(0.71, 1.16)
Leisure activities								
None	215 (21%)	795 (79%)	1.00	(ref)	1.00	(ref)	1.00	(ref)
Intermittent	296 (19%)	1247 (81%)	1.05	(0.84, 1.30)	1.15	(0.92, 1.43)	1.16	(0.93, 1.44)
Consistent	225 (16%)	1224 (84%)	0.86	(0.68, 1.08)	1.03	(0.81, 1.31)	1.07	(0.83, 1.36)
Cultural activities								
None	202 (27%)	557 (73%)	1.00	(ref)	1.00	(ref)	1.00	(ref)
Intermittent	294 (21%)	1128 (79%)	0.83	(0.66, 1.03)	0.85	(0.68, 1.06)	0.87	(0.69, 1.09)
Consistent	240 (13%)	1581 (87%)	0.59	(0.46, 0.76)	0.65	(0.50, 0.84)	0.70	(0.54, 0.91)

*Adjusted for age, sex, ethnicity, educational attainment, occupational class, self-rated eyesight, having a limiting long-standing illness, and experiencing an IADL limitation over the follow-up

†Model 1 + Internet use and engagement in each of civic, leisure, and cultural activities

‡Model 2 + baseline memory, baseline verbal fluency, memory decline, and verbal fluency decline

Table 9.4 Additive effects of consistent engagement in any of internet use, civic activities, leisure activities, and cultural activities, waves 2 to 5, n=4002

	OR*	95% CI
Per additional activity	0.87	(0.80, 0.95)
Number of activities engaged in		
None	1.00	
One	0.88	(0.71, 1.10)
Two	0.78	(0.60, 1.01)
Three	0.68	(0.50, 0.93)
Four	0.53	(0.34, 0.83)

*Adjusted for age, sex, ethnicity, educational attainment, occupational class, having a limiting long-standing illness, experiencing an IADL limitation, baseline memory, baseline verbal fluency, memory decline, and verbal fluency decline

9.4 Discussion

In this longitudinal cohort study of older English adults aged 52 and over, consistent Internet use and engagement in cultural activities including attending the theatre, cinema, art galleries, museums, concerts, or opera at least once a year were individually associated with ageing-related health literacy decline in a protective manner. As the number of activities engaged in increased, the protective association with health literacy decline increased in magnitude. When all four of Internet use, civic activities, leisure activities, and cultural activities were consistently engaged in, the protective association was the strongest. These relationships were independent of cognitive function and decline.

At the time when I originally conducted this analysis (summer 2014), the longitudinal relationships between Internet use, social engagement, and health literacy had never been investigated, particularly never among an ageing sample. More recently, a longitudinal analysis of data from the US Health and Retirement Study (HRS; the sister study to ELSA) found that Internet use in 2009 was predictive of REALM-assessed health literacy in 2010 among Americans aged 65 and over, independently of sociodemographic factors, cognitive impairment, and physical health (Levy, Janke, & Lange, 2014). In this study, both use of Internet at all, and specific use of the Internet to obtain health or medical information positively predicted health literacy (Levy et al., 2014). My hypothesis regarding Internet use and health literacy decline was supported, consistent with this study as well as two existing cross-sectional studies (Echt & Burridge, 2011; Wister et al., 2010). It appears from this analysis that the relationship between Internet use and health literacy decline is only partly explained by measures of memory and verbal fluency. Although I could not investigate these specific pathways, Internet use may also promote health literacy skills through:

a) Providing opportunities for health knowledge acquisition; and/or
b) Improving other cognitive functions such as reasoning; and/or
c) Providing social benefits through social media and networking sites; and/or
d) Training the specific navigational and digital skills required to use the Internet

My hypothesis that intellectually stimulating social engagement would be protective against health literacy decline was mostly supported. It may be that the categories in the leisure activity domain were too general to observe an association, and/or that they involved passive engagement, which has no effect on cognitive function (Park et al., 2014). With respect to cultural activities, these would likely engage several fluid cognitive functions depending on the specific show or exhibit. Importantly, the association I observed was independent of education, occupational class, having a limiting long-standing illness, or experiencing IADL limitations over the follow-up, indicating that cultural engagement is not simply a proxy for socioeconomic circumstances or good physical capability.

Although additional studies with more comprehensive cognitive function measures are needed, I found that Internet use and social engagement were associated with health literacy independently of memory and verbal fluency measures. However, health literacy has recently been postulated to be little more than a marker of cognitive ability (Mõttus et al., 2014; Reeve & Basalik, 2014). My findings suggest that even if this were the case, it would be premature to assume an overly deterministic view of health literacy. Ignoring health literacy, and by extension all literacy, as an innate or pre-determined ability would be a disservice to all those who experience literacy-based barriers to health and well-being in society. This chapter highlights the usefulness of putting health literacy in context of both cognitive and social functions, particularly when trying to better understand changes to health literacy skills in later life.

9.4.1 Limitations

With respect to the health literacy measure, the limitations of this study are the same as those in Chapter 8. The chance of a type I error may be slightly inflated in this study due to the multiple associations I tested (29 ORs with a type I error rate of 5% means that 1.45 ORs may be spurious). Non-response bias and attrition bias are also potential limitations of this study. Older, non-white, and less-educationally qualified adults were underrepresented in wave 2 of ELSA (81.5% response rate) and were more also likely to drop out of the study between waves 2 and 5. These demographic factors were significantly associated with Internet use, social engagement, and health literacy decline. Therefore, I may have underestimated the magnitudes of the protective associations that were observed between Internet use and social engagement and health literacy decline, due to differential study attrition; although the use of population weights helped to make the study population as representative as possible of the target population of English adults aged 50 years and over.

Of the 5125 participants who were eligible for inclusion in this study, 20% (1001/5125) did not return the self-completion questionnaire at one or more time point and were subsequently excluded due to missing data on Internet use and social engagement. The characteristics independently associated with non-return of the self-completion questionnaire at one or more time point, in a population-weighted multivariable-adjusted logistic regression model predicting self-completion questionnaire return (non-return vs. return) adjusted for age, sex, ethnicity, educational attainment, occupational class, limiting long-standing illness, IADL limitations, self-rated eyesight, cognitive function, cognitive decline, and health literacy decline, were: non-white ethnicity (OR=5.54; 95% CI: 3.42–8.98 vs. white), having no educational qualifications (OR=1.46; 95% CI: 1.14–1.86 vs. degree level education), having fair/poor/blind eyesight (OR=1.34; 95% CI: 1.05–1.70 vs. excellent/very good/good), memory decline (OR=1.34; 95% CI: 1.12–1.60 yes vs. no), baseline memory (OR=0.95; 95% CI: 0.93–0.98 per increasing point), and baseline verbal fluency (OR=0.94; 95% CI: 0.89–0.98 per increasing point). Consequently, participants with these characteristics were underrepresented in the analysis; I dealt with this by using population-representative weights in the multivariable logistic regression analyses. Fortunately, health literacy decline was not independently associated with non-return of the self-completion questionnaire (OR=1.12; 95% CI: 0.92–1.36). I therefore do not expect that the missing data due to questionnaire non-return have a major impact on my results.

I was unable to measure specific activities within each domain of social engagement (e.g. specific types of volunteer work, educational classes, and theatre shows). The cognitive demands of specific activities would vary, which could have caused a non-differential misclassification biasing of the results to the null. For example, educational classes that might involve learning a new skill such as a language, or intellectually stimulating museum visits that involve active learning of new knowledge (which are thought to promote cognitive function and health literacy) would have been combined in my measure with more intellectually passive activities such as attendance at social clubs or at non-stimulating theatre shows or films (which are thought to have no effect on cognitive function or health literacy). Also, I did not have any detailed data on Internet use such as frequency, duration, and purpose of use. This important lack of information and the potential for reverse causality due to the longitudinal, but not necessarily causal models limit the extent to which I and others can make hypotheses about the specific cognitive learning processes through which health literacy may be improved.

9.4.2 Strengths

This longitudinal study investigated modifiable behavioural practices that may help older adults to maintain functional health literacy during ageing, regardless of ageing-related cognitive decline. The practices investigated in this study – Internet use and social engagement – were selected due to their established associations with cognitive function in older adults and probable associations with health literacy. My results demonstrate independent associations between these practices and the maintenance of fluid health literacy skills over time during ageing. However, whether my results represent direct effects on health literacy skills independently of cognitive function, or a mediated effect by aspects of cognitive functions that were not measured is unknown. For example, there was no measure of reasoning available in the ELSA. Several potential confounding variables such as sociodemographic and health-related factors were adjusted for, and regression models were population-weighted to account for differential study response, attrition, and missing data. On the whole, these results open up several areas of inquiry regarding the mechanisms through which Internet use and social engagement may influence health literacy skills during ageing.

9.4.3 Conclusions

The results from this chapter indicate that Internet use and social engagement may help older adults to maintain the functional literacy skills required to manage health during ageing. Individually, Internet use and cultural engagement appeared to have beneficial associations with health literacy. Together, all four factors appeared to act in an additive fashion, with the more the better for maintaining health literacy skills. Further studies with additional cognitive, technological, and social measures are needed for consideration alongside this one. The socially embedded and intersecting problems of low Internet use, low social engagement, and health literacy decline are complex and will likely require multi-modal interventions to overcome. As an early longitudinal investigation in this area, this study should allow new hypotheses about the social and cognitive processes that influence the dynamics of health literacy at older ages, and how they may be modified. These data will have to come from a data source other than the ELSA, which does not have further in-depth information in these areas.

In sum, the first three empirical chapters of this thesis have indicated that: low health literacy occurs in about one-third of older English adults; fluid health literacy skills decline in about one-fifth of older English adults over a six-year period during ageing; cognitive function and decline play important roles in health literacy decline; marked social inequalities in health literacy decline occur; and, that health literacy decline is not inevitable, with Internet use and social engagement appearing to be protective factors against health literacy decline. The more practices engaged in, the stronger the association with the maintenance of fluid health literacy skills, independently of cognitive function and cognitive decline.

Now, for the remaining empirical chapters, the focus of this thesis will shift to the health behavioural outcomes of low health literacy and health literacy decline during ageing. Chapter 10 will examine the roles of low health literacy and ageing-related health literacy decline in the uptake of colorectal cancer screening in England's NHS Bowel Cancer Screening Programme and Chapter 11 will examine the roles of low health literacy and ageing-related health literacy decline in the long-term maintenance of health-promoting lifestyle behaviours: weekly moderate-to-vigorous physical activity, daily intake of five fruit and vegetable servings, non-problematic alcohol intake, and non-smoking.

Chapter 10. Study 4: Health literacy and colorectal cancer screening in England[8]

10.1 Background

The first three empirical chapters of this thesis established that health literacy skills may decline during ageing after about age 65 years, most commonly among men and adults from socially deprived backgrounds, and that health literacy decline is mostly explained by ageing-related decline in memory and verbal fluency. Low health literacy was prevalent in about one-third of English adults aged 52 years and over, and health literacy decline occurred in one-fifth of adults. These studies also demonstrated that health literacy decline is not inevitable, and that sustained Internet use and engagement in social activities may help to prevent health literacy decline during ageing, independently of cognitive function and decline. Particularly because low health literacy and health literacy decline most commonly occurred among socially disadvantaged older adults, it is important to establish the roles of these two factors in health-related outcomes, as they may contribute to health inequalities.

The latter two empirical chapters of this thesis will focus on the potential health behavioural outcomes of low health literacy and health literacy decline. Low health literacy has consistently been associated with health outcomes related to the management of illness among older adults, such as poor chronic disease knowledge and management, incorrect taking of prescription medications, and high usage of emergency services (Berkman et al., 2011; Davis et al., 2006; M. Williams et al., 1998). It has also been robustly associated with increased risk of all-cause mortality among older adults in the US and the UK (D. W. Baker et al., 2008; Bostock & Steptoe, 2012; Sudore et al., 2006). However, its relationships with outcomes related to the promotion of good health are less well understood. Health literacy has been postulated to be associated with health behavioural outcomes through influencing the motivational and volitional phases of behaviour (Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009a), but the overall associations between health literacy and health-promoting behaviours have not been established. This chapter will focus on the potential role of health literacy in predicting uptake of colorectal cancer (CRC; also called bowel cancer) screening based on the faecal occult blood test (FOBt) in the NHS Bowel Cancer Screening Programme (NHS BCSP) in England.

[8] A version of this Chapter has been published in *Prev Med* (Appendix 10.1).

With over 95% of CRC cases in the UK occurring in adults aged over 50 and over half of CRC deaths being preventable partly through screening, improving CRC screening uptake is of great importance for the health and well-being of the older population in England (Cancer Research UK, 2015). England is one of the first countries worldwide to implement a national, organised CRC screening programme using the FOBt. The screening programme is administered by the NHS and was fully implemented country-wide in 2010. All adults aged 60-74 years are eligible and receive a written screening invitation letter in the post, along with an informational leaflet (‘*Bowel Cancer Screening: The Facts*’) on their 60th or 61st birthday, and biennially thereafter. The original age range was 60-69 years during the programme implementation from 2006 to 2010, and was extended up to age 74 years from 2010. The ‘*Facts*’ leaflet is intended to provide information for people to make an informed choice about screening, including information on bowel cancer risk, the purpose of screening, the harms and benefits of the test, the likelihood of a positive test, and what happens if the screening test is positive. About two weeks after the invitation letter and the ‘*Facts*’ leaflets are sent in the post, the home-based FOBt and instructions on how to complete it and send it back arrive. This home-based modality of the screening test is intended to reduce time and transport barriers to participation in screening that can occur with clinic-based screening test appointments.

Although the home-based aspect of the FOBt aims to reduce barriers to participation, overall uptake of the test is low and substantially socially graded within the eligible general population. An analysis of the first 2.6 million invitations to the programme from 2006 to 2009 found that overall uptake was 54%, but was substantially lower among men and among adults living in deprived and ethnically diverse neighbourhoods (von Wagner et al., 2011). A further source of inequality in screening participation may be low health literacy. Because the NHS BCSP communicates with all screening-eligible adults entirely through written materials sent out through the post, without any in-person contact from a health care professional as there would be in a clinic-based screening appointment, low health literacy may be a barrier to participating in CRC screening. Given that low health literacy is known to be more frequent among socially deprived adults, it may in part explain the overall low uptake of screening and the demonstrated social inequalities in screening through inhibiting some individuals’ capacities to understand and engage with the written screening information (Davis et al., 2002; von Wagner et al., 2009a; von Wagner et al., 2011).

Information about cancer screening has been suggested to be ineffective among adults with low health literacy, as they lack the required background knowledge and vocabulary about cancer control to integrate with new information about screening tests that they become eligible for during ageing (Davis et al., 2002). Adults with low health literacy have empirically been found to experience a greater burden of information processing when reading information about CRC screening than those with adequate health literacy (von Wagner et al., 2009b). In keeping with these findings, awareness of and knowledge about CRC screening does not appear to be equally distributed in the screening-eligible adult population with respect to health literacy. In three cross-sectional American studies, older adults with high health literacy had greater awareness and knowledge of screening tests than those with low health literacy (Agho et al., 2012; Dolan et al., 2004; N. S. Morris et al., 2013). However, these studies did not provide multivariable-adjusted results, so it is unclear whether differences in awareness and knowledge according to health literacy simply reflected differing sociodemographic make-up of the high and low health literacy groups within the studies.

In three other American studies on the same topic, which did adjust for sociodemographic factors, findings were inconsistent. Limited health literacy, according to the REALM, was negatively associated with being able to name and describe at least one CRC screening test in one study (Miller et al., 2007), but not in two others (Guerra, Dominguez, & Shea, 2007; Peterson et al., 2007). In one of these studies, limited health literacy was independently associated with experiencing more barriers to FOBt screening, including not understanding what to do, finding the test embarrassing or time consuming, being afraid of pain or finding something wrong, being concerned about cost, having transportation problems, and not feeling that anything is wrong (Peterson et al., 2007). In another American study using the REALM, limited health literacy was independently associated with lower self-efficacy to obtain a testing kit, as well as a lower ability to name and describe at least one CRC screening test, and less agreement that detecting CRC screening early is helpful (Arnold et al., 2012). The former three studies were of convenience samples of about 100 participants each, who were aged ≥50 years and recruited from medical centres (Guerra et al., 2007; Miller et al., 2007; Peterson et al., 2007). The fourth study was a randomised controlled trial with a much larger sample size of over 900 participants who were recruited from socioeconomically deprived and ethnic minority communities to achieve a better representation of adults with low health literacy skills (Arnold et al., 2012). The differences in sample compositions may explain the discordant results between studies, as the latter study had greater variation in health literacy skills of the sample.

To date, existing evidence on the direct association between health literacy and uptake of CRC screening has been mixed. In two of the above studies, limited health literacy was negatively associated with participation in FOBt screening for CRC (Arnold et al., 2012; Guerra et al., 2007), but there was no association observed between health literacy and FOBt screening in two others (Miller et al., 2007; Peterson et al., 2007). These studies were all undertaken in America, where cancer screening had not been freely available to adults without private health care insurance or Medicare (public health insurance for adults aged ≥65 years) or Medicaid (public health insurance for adults with low income). The role of health literacy as a determinant of cancer screening uptake in the context of freely available screening in a public system is unknown.

The analyses presented in this chapter aimed to investigate the roles of health literacy and health literacy decline in predicting uptake of FOBt screening for CRC in England's NHS BCSP, independently of sociodemographic factors, health-related factors, and cognitive function. There is no direct contact with a health professional as an organised part of the BCSP, in contrast to the breast and cervical screening programmes in England, which are appointment-based and the person has an opportunity to discuss the test with a professional at their appointment. I therefore hypothesised that health literacy would influence the uptake of screening specifically in the BCSP as opposed to other types of cancer screening. In this chapter, I hypothesised that adults with high health literacy and who do not decline in health literacy over time will be more likely to participate in FOBt screening than those with low health literacy and who decline in health literacy over time. I also hypothesised that these associations would be independent of cognitive function, as I thought health literacy would have a direct effect on reading, understanding, and using information to make a decision about screening.

10.2 Methods

10.2.1 Sample

There are two ELSA samples used in this chapter, for two separate analyses: 1) low health literacy and FOBt screening (Sample 1), and 2) health literacy decline and FOBt screening (Sample 2). For Sample 1, all core ELSA participants who completed data collection at waves 5 (2010/11) and 6 (2012/13) with non-proxy interviews and were within the eligible age range for screening were eligible for inclusion, to utilise the health literacy measure at wave 5 and the FOBt screening uptake measure at 6 (Table 10.1). For Sample 2, all core ELSA participants who completed data collection at waves 2 (2004/05), 5 (2010/11) and 6 (2012/13) with non-proxy interviews and were within the eligible age range for screening were eligible for inclusion, to utilise the health literacy decline measure from waves 2 and 5, and the FOBt screening uptake measure at wave 6 (Table 10.2).

Table 10.1 Timing of measurements for Sample 1

Variables	Wave 2 (2004/05)	Wave 3 (2006/07)	Wave 4 (2008/09)	Wave 5 (2010/11)	Wave 6 (2012/13)
Health literacy				X	
Covariates				X	
FOBt screening					X

Note: FOBt screening from 2010 and 2013 was assessed in 2012/13

Table 10.2 Timing of measurements for Sample 2

Variables	Wave 2 (2004/05)	Wave 3 (2006/07)	Wave 4 (2008/09)	Wave 5 (2010/11)	Wave 6 (2012/13)
Health literacy	X				
Health literacy decline	X			X	
Covariates	X				
FOBt screening					X

Note: FOBt screening from 2010 and 2013 was assessed in 2012/13

Since 2010, men and women aged 60-74 years have been eligible for FOBt screening. Therefore, all ELSA participants aged 60-74 at wave 5 (2010/11) were eligible for inclusion in this chapter. The two samples are described separately below:

10.2.1.1 Sample 1: Low health literacy and FOBt screening

Of the 9090 core participants present in the ELSA sample at wave 5, 4899 (53.9%) were aged 60 to 74 years. Of these, 4438 (90.6%) remained in the study two years later at the wave 6 follow-up, giving an attrition rate of 9.4%. Of the remaining 4438 participants, 140 (3%) had proxy interviews either at wave 5 (n=89) or wave 6 (n=116). In total, 4238 participants were within the eligible age range for FOBt screening in England’s national programme and remained in the study between waves 5 and 6 with non-proxy interviews. Because the vast majority of reported screening episodes occurred in 2010 or later (n=2837/2995; 94.7%), the wave 5 health literacy measure was used to ensure that the measure of health literacy used in the analysis reflected health literacy around the time of FOBt participation.

10.2.1.2 Sample 2: Health literacy decline and FOBt screening

The sample of 5256 participants used in Chapter 8 was restricted to those aged 60 to 74 years at wave 5, and then followed forward to wave 6 to obtain the measure of FOBt screening uptake for this analysis. Of the 5256 participants that were in the ELSA with complete health literacy data and non-proxy interviews at waves 2 and 5, 3346 (63.7%) were aged 60 to 74 years and eligible for inclusion in this analysis. Of these, 3092 (92.4%) remained in the study at wave 6. Of these, 28 (1%) participants had a proxy interview at wave 6 and were excluded. Thus, the final eligible sample for the analysis of health literacy decline and FOBt screening was 3092 participants.

10.2.2 Measures

10.2.2.1 Health literacy

As in the previous chapters, health literacy was assessed using a four-item measure from the Adult Literacy and Life Skills Survey developed by the OECD and Statistics Canada (Thorn, 2009). For the analysis of low health literacy and FOBt screening uptake (Sample 1), health literacy was categorised as ‘Low’ (0-2 items correct), ‘Medium’ (3 items correct), and ‘High’ (4 items correct). This categorisation allows examination of whether there is a threshold beyond which health literacy skills might affect FOBt screening uptake. This categorisation of the health literacy variable in the ELSA has been previously associated with risk of all-cause mortality over a five-year follow-up period in a linearly graded fashion, demonstrating its predictive capability for important health outcomes (Bostock & Steptoe, 2012).

A current area in methodological research on health literacy is the threshold vs. graded nature of relationships between literacy and health outcomes across the entire spectrum of literacy. It has been unclear whether literacy affects health-related outcomes with a threshold effect, whereby literacy skills below a certain level have an equal effect on the likelihood of an outcome, or, whether there is a graded, incremental effect of low health literacy across skill levels. The nature of the relationship may depend on the outcome in question. Previous research has shown that health literacy has a negatively graded effect on physical functioning, but a marked threshold effect on mental health (Wolf, Feinglass, Thompson, & Baker, 2010). Hence, linear trend tests will be run to assess if there is a graded or a threshold relationship between health literacy and FOBt screening uptake in this sample.

In the analysis of health literacy decline and FOBt screening uptake, health literacy decline was defined the same way as in Chapters 8 and 9, as a decrease of ≥1 point in score on the health literacy measure between waves.

10.2.2.2 FOBt screening uptake

At the wave 6 study interview, participants were asked, '*Have you ever completed a home testing kit for screening bowel cancer?*' with response options of 'yes' or 'no'. If the response was 'yes', they were asked, '*How long ago was your most recent test?*' with response options in years and months. Then, they were asked, '*Was this test part of the NHS Bowel Cancer Screening Programme?*' with response options of 'yes' or 'no'. The outcome variable for this study was yes vs. no for FOBt screening uptake since 2010. This time period restriction was done to ensure that the measurement of screening uptake (outcome variable) did not precede the measurement of health literacy ('exposure' variable) in the analyses for both of Sample 1 and Sample 2. The majority of reported FOBt screening episodes took place in 2010 or later (n=2837/2995; 94.7%). The predictors of FOBt screening since 2010 were the same as those of FOBt screening since 2006, when the screening programme was introduced; the predictors of screening since 2010 are shown in this Chapter and the predictors of screening since 2006 are shown in Appendix 10.2 for comparison.

10.2.2.3 Covariates

The same sociodemographic covariates that were assessed in Chapters 8 and 9 were used in this chapter, to ensure consistency of the analyses: age (continuous from 60 to 74), sex (male; female), ethnicity (white; non-white), educational attainment (degree or equivalent; up to degree level; no qualification), occupational class according to the three-category UK National Statistics Socioeconomic Classification (managerial; intermediate; routine), net non-pension wealth calculated in quintiles stratified at age 65 to account for the effect of retirement on wealth, and marital status (single; married or living as married). Several health-related variables were also included, as they would be plausibly be confounders of any relationship between health literacy and uptake of FOBt screening: having a limiting long-standing illness (yes; no), a limitation in any one of six activities of daily living (ADLs)[9] (yes; no), a limitation in any one of nine instrumental activities of daily living

[9] The six ADLs were: dressing including putting on shoes and socks, walking across a room, bathing or showering, feeding oneself such as cutting up food, getting in and out of bed, and using the toilet, including getting up or down.

(IADLs)[10] (yes; no), having depressive symptoms, defined as scoring more than four on the eight-item Centre for Epidemiologic Studies depression scale (yes; no) (Radloff, 1977), self-rated general health (Fair/Poor; Excellent/Very Good/Good), self-rated eyesight (Fair/Poor/Blind; Excellent/Very Good/Good), and having ever been diagnosed with cancer (yes; no).

All covariates were assessed at wave 5 for the analysis of low health literacy and FOBt screening and at wave 2 for the analysis of health literacy decline and FOBt screening. The variables were same for both analyses, except for the ADL and IADL variables were combined into a single variable for the health literacy decline analysis, due to the way ADLs and IADLs measures were coded at wave 2.

The cognitive function covariates were the same as in Chapters 8 and 9. For the analysis of low health literacy and FOBt uptake, memory (combined score on the time orientation, immediate recall, and delayed recall tests, out of 24) and verbal fluency (out of 9) at wave 5 were included. For the analysis of health literacy decline and FOBt uptake, memory and verbal fluency scores at wave 2 and decline in memory and verbal fluency scores between waves 2 and 5 were included.

10.2.3 Statistical analysis

10.2.3.1 Sample 1: Low health literacy and FOBt screening

The prevalences of low, medium, and high health literacy at wave 5 were calculated. Unadjusted multinomial logistic regression was used to estimate ORs and 95% CIs for the associations between health literacy (medium vs. low and high vs. low) and all covariates. The same analyses were conducted for uptake of FOBt screening (yes vs. no) and all covariates. The independent associations between health literacy (medium vs. low and high vs. low) and uptake of FOBt screening (yes vs. no) were then estimated using multivariable-adjusted logistic regression. Age, sex, educational attainment, and net non-pension wealth were forced into and retained in the model. Age and sex were forced into the model due to their importance as key sociodemographic factors, education was forced in the model to prevent any confounding by education, and net non-pension wealth was forced in due to the established importance of socioeconomic deprivation in the uptake of FOBt

[10] The nine IADLs were: using a map to figure out how to get around a strange place, preparing a hot meal, shopping for groceries, making phone calls, taking medications, doing work around the house and garden, managing money such as paying bills and keeping track of expenses, recognising when in physical danger, and communicating (using speech, hearing, or eyesight).

screening (von Wagner et al., 2011). Net non-pension wealth quintile was added as continuous variable into all models, as it was positively linearly associated with FOBt screening uptake. All other covariates that were associated with FOBt screening uptake with $p<0.20$ in bivariate analysis, with the exception of cognitive function variables, were included in the initial multivariable-adjusted model. Covariates that were statistically non-significant were removed (i.e. $p \geq 0.05$ for association with FOBt screening) if their deletion did not result in a ≥10% change in the OR between health literacy and FOBt screening uptake (Rothman & Greenland, 2008). The cognitive function variables were then included in a second set of models, to assess the degree to which their inclusion in the final model explained any relationship between health literacy and uptake of FOBt screening.

10.2.3.2 Sample 2: Health literacy decline and FOBt screening

For the analysis of health literacy decline and FOBt screening, the above process was mostly repeated. As the associations between health literacy decline and covariates have been shown in Chapter 8, and the associations between FOBt screening and covariates were shown in the above sample, these modelling steps were skipped. The independent association between health literacy decline and uptake of FOBt screening was estimated using multivariable-adjusted logistic regression. Again, age, sex, educational attainment, and net non-pension wealth were forced into and retained in the model. All other covariates associated with FOBt screening uptake with $p<0.20$ in bivariate analysis, with the exception of cognitive function and decline variables, were included in the initial model. Covariates that were statistically non-significant were removed (i.e. $p \geq 0.05$ for association with FOBt screening) if their deletion did not result in a ≥10% change in the OR between health literacy decline and FOBt screening uptake (Rothman & Greenland, 2008) The cognitive function and cognitive decline variables were included in two additional sets of models, to assess the degree to which their inclusion in the final model explained any relationship between health literacy decline and uptake of FOBt screening. All analyses were conducted using StataSE 13.1 (StataCorp, College Station, TX).

10.3 Results

10.3.1 Missing data

Of the 4298 participants eligible for the analysis of low health literacy and FOBt screening uptake (Sample 1), 4189 (97.5%) completed the health literacy assessment. Common non-completion reasons were sight difficulties (n=20), health problems (n=15), reading problems (n=28), and declining to complete the assessment (n=24). For this analysis, those who were unable to complete the health literacy assessment due to problems with health, sight, or reading were included and scoring 0/4 on the measure, as they would likely perform with low health literacy in real-life everyday situations (n=85). Those who declined the health literacy assessment were excluded (n=24), to give a final sample of 4274 participants with complete health literacy data. Three participants were missing data on ethnicity (<1%), 31 on occupational class (<1%), and 234 on net non-pension wealth (9.5%). 14 participants were missing data on memory function and 22 participants were missing data on verbal fluency (<1%). No other variables were missing data. All data were missing on a case-by-case basis, with the final sample size including 4274 participants.

Of the 3064 participants who were eligible for the analysis of health literacy decline (Sample 2), one was missing data on ethnicity (<1%), one on education (<1%), two on occupational class (<1%), and 172 on net-non pension wealth (5.6%). All data were missing on a case-by-case basis, with the final sample size including 3064 participants.

10.3.2 Sample 1: Low health literacy and FOBt screening

Table 10.3 shows the characteristics of the ELSA sample included in the analysis of low health literacy and FOBt screening uptake. Overall, 424/4274 (10%) had ‘low’ health literacy, 627/4274 (15%) had ‘medium’ health literacy, and 3223/4274 (75%) had ‘high’ health literacy. The mean age was 66.4 (SD 4.3) years, just over half the sample was female (2335/4274; 55%), the vast majority were white (4168/4271; 98%), 24% had no educational qualifications (1025/4274), 49% had up to degree-level education (2083/4274), and 27% had degree-level education (1166/4274). Nearly three-quarters were married or living as married (3127/4274; 73%), and most were in good health according to all of the health-related measures (Table 10.3).

Table 10.3 Characteristics of the sample, n=4274

Characteristic	N (%)
Health literacy	
Mean (SD)	3.6 (0.8)
Low	424 (10%)
Medium	627 (15%)
High	3223 (75%)
Age	
Mean (SD)	66.4 (4.3)
Sex	
Female	2335 (55%)
Male	1939 (45%)
Ethnicity	
Non-white	105 (2%)
White	4168 (98%)
Educational attainment	
No qualifications	1025 (24%)
Up to degree level	2083 (49%)
Degree level	1166 (27%)
Occupational class	
Routine	1714 (40%)
Intermediate	1089 (26%)
Managerial/Professional	1441 (34%)
Net non-pension wealth quintile	
1 (poorest)	677 (17%)
2	781 (19%)
3	799 (20%)
4	843 (21%)
5 (richest)	940 (23%)
Marital status	
Single	1147 (27%)
Married or living as married	3127 (73%)
Limiting longstanding illness	
Yes	1364 (32%)
No	2910 (68%)
ADL limitations	
Yes	633 (15%)
No	3641 (85%)
IADL limitations	
Yes	448 (10%)
No	3826 (90%)
Depressive symptoms	
Yes	1090 (25%)
No	3184 (75%)
Self-rated general health	
Fair/Poor	963 (23%)
Excellent/Very good/Good	3311 (77%)
Self-rated eyesight	
Fair/Poor/Registered as blind	430 (10%)
Excellent/Very good/Good	3844 (90%)
Ever diagnosed with cancer	
Yes	425 (10%)
No	3849 (90%)
Memory	
Mean (SD)	14.7 (3.4)
Verbal fluency	
Mean (SD)	6.0 (2.1)

Table 10.4 shows the unadjusted associations between all characteristics of the sample and health literacy level, categorised as ‘low’, ‘medium’, and ‘high’. Consistent with the longitudinal analysis of health literacy decline in Chapter 8, women, adults from a white ethnic background, adults with up to degree or degree-level education, adults in a higher occupational class, with better self-rated eyesight, and better memory and verbal fluency were the most likely to have medium or high health literacy (Table 10.4). Age was inversely associated with health literacy (OR=0.94; 95% CI: 0.91–0.97 for medium vs. low health literacy and OR=0.92; 95% CI: 0.89–0.94 for high vs. low health literacy). Wealthier and married adults were also more likely to have medium or high health literacy. Higher health literacy was positively associated with all health-related measures, except there was no association between health literacy and having a previous cancer diagnosis (Table 10.4).

Table 10.4 Unadjusted associations between health literacy and covariates

	Health literacy level						
	Low (424; 10%)	Medium (627; 15%)	High (3223; 75%)	OR (95% CI)* Medium vs. Low	*p*-value	OR (95% CI)* High vs. Low	*p*-value
Age							
Mean (SD)	67.8 (4.4)	66.6 (4.3)	66.1 (4.2)	0.94 (0.91, 0.97)	<0.0001	0.92 (0.89, 0.94)	<0.0001
Sex							
Male	223 (12%)	281 (14%)	1435 (74%)	1.00 (ref)		1.00 (ref)	
Female	201 (9%)	346 (15%)	1788 (77%)	1.37 (1.07, 1.75)	0.013	1.38 (1.13, 1.69)	0.002
Ethnicity							
Non-white	35 (33%)	17 (16%)	53 (50%)	1.00 (ref)		1.00 (ref)	
White	388 (9%)	610 (15%)	3170 (76%)	3.24 (1.79, 5.86)	<0.0001	5.40 (3.48, 8.38)	<0.0001
Educational attainment							
No qualification	208 (20%)	216 (21%)	601 (59%)	1.00 (ref)		1.00 (ref)	
Up to degree level	144 (7%)	294 (14%)	1645 (79%)	1.97 (1.49, 2.59)	<0.0001	3.95 (3.13, 4.99)	<0.0001
Degree or equivalent	72 (6%)	117 (10%)	977 (84%)	1.56 (1.10, 2.22)	0.012	4.70 (3.53, 6.25)	<0.0001
Occupational class							
Routine	277 (16%)	309 (18%)	1128 (66%)	1.00 (ref)		1.00 (ref)	
Intermediate	83 (8%)	153 (14%)	853 (78%)	1.65 (1.21, 2.26)	0.002	2.52 (1.94, 3.28)	<0.0001
Managerial	56 (4%)	161 (11%)	1224 (85%)	2.58 (1.83, 3.64)	<0.0001	5.37 (3.98, 7.23)	<0.0001
Net non-pension wealth fifth							
1 (poorest)	112 (17%)	132 (20%)	433 (64%)	1.00 (ref)		1.00 (ref)	
2	92 (12%)	117 (15%)	572 (73%)	1.08 (0.74, 1.56)	0.69	1.61 (1.19, 2.18)	0.002
3	67 (8%)	116 (15%)	616 (77%)	1.47 (0.99, 2.17)	0.06	2.38 (1.72, 3.30)	<0.0001
4	58 (7%)	116 (14%)	669 (79%)	1.70 (1.13, 2.54)	0.01	2.98 (2.13, 4.19)	<0.0001
5 (richest)	51 (5%)	99 (11%)	790 (84%)	1.65 (1.08, 2.51)	0.02	4.01 (2.82, 5.69)	<0.0001
Marital status							
Single	145 (13%)	174 (15%)	828 (72%)	1.00 (ref)		1.00 (ref)	
Married or living as married	279 (9%)	453 (14%)	2395 (77%)	1.35 (1.04, 1.77)	0.03	1.50 (1.21, 1.87)	<0.0001
Limiting longstanding illness							
Yes	192 (14%)	222 (16%)	950 (70%)	1.00 (ref)		1.00 (ref)	
No	232 (8%)	405 (14%)	2273 (78%)	1.51 (1.17, 1.94)	0.001	1.98 (1.61, 2.43)	<0.0001
ADL limitations							
Yes	106 (17%)	114 (18%)	413 (65%)	1.00 (ref)		1.00 (ref)	
No	318 (9%)	513 (14%)	2810 (77%)	1.50 (1.11, 2.02)	0.008	2.27 (1.78, 2.89)	<0.0001

IADL limitations							
Yes	91 (20%)	71 (16%)	286 (64%)	1.00 (ref)		1.00 (ref)	
No	333 (9%)	556 (15%)	2937 (77%)	2.14 (1.53, 3.00)	0.05	2.81 (2.16, 3.65)	<0.0001
Depressive symptoms							
Yes	167 (15%)	182 (17%)	741 (68%)	1.00 (ref)		1.00 (ref)	
No	257 (8%)	445 (14%)	2482 (78%)	1.59 (1.22, 2.06)	<0.0001	2.18 (1.76, 2.69)	<0.0001
Self-rated general health							
Fair/poor	178 (18%)	183 (19%)	602 (63%)	1.00 (ref)		1.00 (ref)	
Excellent/very good/good	246 (7%)	444 (13%)	2621 (79%)	1.76 (1.36, 2.27)	<0.0001	3.15 (2.55, 3.90)	<0.0001
Self-rated eyesight							
Fair/poor/blind	84 (20%)	82 (19%)	264 (61%)	1.00 (ref)		1.00 (ref)	
Excellent/very good/good	340 (9%)	545 (14%)	2959 (77%)	1.64 (1.18, 2.29)	0.004	2.77 (2.11, 3.63)	<0.0001
Ever diagnosed with cancer							
Yes	40 (9%)	56 (13%)	329 (77%)	1.00 (ref)		1.00 (ref)	
No	384 (10%)	571 (15%)	2894 (75%)	1.06 (0.69, 1.63)	0.78	0.92 (0.65, 1.29)	0.62
Memory							
Mean (SD)	11.7 (4.1)	13.9 (2.9)	15.3 (3.2)	1.19 (1.14, 1.23)	<0.0001	1.36 (1.31, 1.40)	<0.0001
Verbal fluency							
Mean (SD)	4.6 (2.3)	5.5 (2.0)	6.3 (2.0)	1.22 (1.15, 1.29)	<0.0001	1.46 (1.39, 1.53)	<0.0001

[*] Unadjusted

Table 10.5 shows the unadjusted associations between all covariates and FOBt screening uptake from 2010. Overall, uptake from 2010 was 66% (2837/4274). Women, adults from a white ethnic background, adults with up to degree or degree-level education, adults in a higher occupational class and higher net non-pension wealth, and who were married were the most likely to have participated in FOBt screening (Table 10.5). Uptake of FOBt screening was also positively associated with all of the health-related variables, and with having better memory and verbal fluency scores. The predictors of ‘ever’ screening uptake since 2006 (70% of the sample; 2995/4274) are shown in Appendix 10.2.

Table 10.5 Unadjusted associations between FOBt screening and covariates

Characteristic	FOBt screening uptake Yes (2837; 66%)	No (1437; 34%)	OR (95% CI)* Yes vs. No
Health literacy			
Low	222 (52%)	202 (48%)	1.00 (ref)
Medium	391 (62%)	236 (38%)	1.51 (1.17, 1.94)
High	2224 (69%)	999 (31%)	2.03 (1.65, 2.49)
Age			
Mean (SD)	65.5 (3.8)	68.1 (4.6)	0.86 (0.85, 0.88)
Sex			
Male	1245 (64%)	694 (36%)	1.00 (ref)
Female	1592 (68%)	743 (32%)	1.19 (1.05, 1.36)
Ethnicity			
Non-white	2778 (67%)	1390 (33%)	1.00 (ref)
White	58 (55%)	47 (45%)	1.62 (1.10, 2.39)
Educational attainment			
No qualification	567 (55%)	458 (45%)	1.00 (ref)
Up to degree level	1441 (69%)	642 (31%)	1.81 (1.55, 2.12)
Degree or equivalent	829 (71%)	337 (29%)	1.99 (1.67, 2.37)
Occupational class			
Routine	1078 (63%)	636 (37%)	1.00 (ref)
Intermediate	721 (66%)	368 (34%)	1.16 (0.99, 1.36)
Managerial	1022 (71%)	419 (29%)	1.44 (1.24, 1.67)
Net non-pension wealth quintile			
1 (poorest)	373 (55%)	304 (45%)	1.00 (ref)
2	510 (65%)	271 (35%)	1.53 (1.24, 1.89)
3	550 (69%)	249 (31%)	1.80 (1.45, 2.23)
4	595 (71%)	248 (29%)	1.96 (1.58, 2.42)
5 (richest)	691 (74%)	249 (26%)	2.26 (1.83, 2.79)
Marital status			
Single	643 (56%)	504 (44%)	1.00 (ref)
Married or living as married	2194 (70%)	933 (30%)	1.84 (1.60, 2.12)
Limiting longstanding illness			
Yes	827 (61%)	537 (39%)	1.00 (ref)
No	2010 (69%)	900 (31%)	1.45 (1.27, 1.66)
ADL limitations			
Yes	370 (58%)	263 (42%)	1.00 (ref)
No	2467 (68%)	1174 (32%)	1.49 (1.26, 1.78)
IADL limitations			
Yes	252 (56%)	196 (44%)	1.00 (ref)
No	2585 (68%)	1241 (32%)	1.62 (1.33, 1.98)
Depressive symptoms			
Yes	670 (61%)	420 (39%)	1.00 (ref)
No	2167 (68%)	1017 (32%)	1.34 (1.16, 1.54)
Self-rated general health			
Fair/poor	543 (56%)	420 (44%)	1.00 (ref)
Excellent/very good/good	2294 (69%)	1017 (31%)	1.56 (1.28, 1.91)
Self-rated eyesight			
Fair/poor/blind	245 (57%)	185 (43%)	1.00 (ref)
Excellent/very good/good	2592 (67%)	1252 (33%)	1.48 (1.20, 1.82)
Ever diagnosed with cancer			
Yes	261 (61%)	164 (39%)	1.00 (ref)
No	2576 (67%)	1273 (33%)	1.27 (1.03, 1.56)
Memory			
Mean (SD)	15.2 (3.3)	13.9 (3.6)	1.12 (1.09, 1.14)
Verbal fluency			
Mean (SD)	6.2 (2.0)	5.6 (2.2)	1.14 (1.11, 1.20)

*Unadjusted

Table 10.6 shows the results from the multivariable-adjusted logistic regression predicting FOBt screening uptake, with health literacy as the main predictor and including all covariates that were statistically significant predictors of FOBt screening. The covariates included in the final model were: age, sex, educational attainment, net non-pension wealth, and marital status. Health literacy was positively associated with FOBt screening uptake in a linearly graded fashion (p_{trend}<0.0001), with OR=1.11 (95% CI: 0.84–1.47) for medium vs. low health literacy and OR=1.30 (95% CI: 1.03–1.65) for high vs. low health literacy (Table 10.6). The other significant predictors of FOBt screening uptake in the adjusted model were: age (OR=0.86; 95% CI: 0.85–0.88 per additional year), female sex (OR=1.31; 95% CI: 1.13–1.51), higher educational attainment (OR=1.22; 95% CI: 0.99–1.50 for degree-level education vs. no qualifications), greater wealth (OR=1.16; 95% CI: 1.09–1.22 per increasing net non-pension wealth quintile), and being married or living as married (OR=1.42; 95% CI: 1.21–1.67; Table 10.6).

When memory and verbal fluency were added to the model, the relationship between health literacy and FOBt screening was attenuated to the null, with OR=1.00 (95% CI: 0.75–1.34) for medium vs. low health literacy and OR=1.12 (95% CI: 0.87–1.44) for high vs. low health literacy (Table 10.6). The ORs for all other sociodemographic covariates were mostly unaltered, except for the relationship with degree-level education, which was also attenuated. Having better memory was positively associated with FOBt uptake, with OR=1.04 (95% CI: 1.02–1.07) per point increase out of 24 on the memory index. Having better verbal fluency was also positively, but borderline statistically significantly associated with FOBt uptake, with OR=1.03 (95% CI: 0.99–1.07; Table 10.6).

Table 10.6 Adjusted logistic regression predicting FOBt uptake

Characteristic	FOBt screening uptake OR 1 (95% CI)* Yes vs. No	OR 2 (95% CI)† Yes vs. No
Health literacy		
Low	1.00 (ref)	1.00 (ref)
Medium	1.11 (0.83, 1.47)	1.00 (0.75, 1.34)
High	1.30 (1.03, 1.64)	1.12 (0.87, 1.44)
Age		
Mean (SD)	0.86 (0.85, 0.88)	0.87 (0.86, 0.89)
Sex		
Male	1.00 (ref)	1.00 (ref)
Female	1.31 (1.13, 1.51)	1.26 (1.09, 1.46)
Educational attainment		
No qualification	1.00 (ref)	1.00 (ref)
Up to degree level	1.26 (1.05, 1.50)	1.18 (0.98, 1.41)
Degree or equivalent	1.22 (0.99, 1.50)	1.12 (0.91, 1.38)
Net non-pension wealth		
Per increasing quintile	1.16 (1.09, 1.22)	1.14 (1.08, 1.20)
Marital status		
Single	1.00 (ref)	1.00 (ref)
Married or living as married	1.42 (1.21, 1.67)	1.42 (1.20, 1.67)
Memory		
Mean (SD)	-	1.04 (1.02, 1.07)
Verbal fluency		
Mean (SD)	-	1.03 (0.99, 1.07)

*Adjusted for health literacy, age, sex, educational attainment, net non-pension wealth fifth, and marital status (n=4040)
†Additionally adjusted for memory and verbal fluency (n=4031)

10.3.3 Sample 2: Health literacy decline and FOBt screening

Table 10.7 shows the characteristics of the sample used to analyse the relationship between health literacy decline and uptake of FOBt screening. The sample characteristics were similar to that of the sample in Chapter 8, as it is the same sample followed forward to wave 6, two years later. Overall, 480/3064 (16%) participants declined in health literacy score between waves 2 and 5. This proportion of health literacy decline is lower than that observed in Chapter 8 (1032/5256; 20%), which is likely because the upper age limit of 74 years in this analysis excluded adults aged 75 years and over, who more frequently declined in health literacy skills than those under age 75 years.

Table 10.7 Characteristics of the sample, n=3064

Characteristic	N (%)
Health literacy decline	
Yes	480 (16%)
No	2584 (84%)
Age	
Mean (SD)	66.3 (4.3)
Sex	
Female	1701 (56%)
Male	1363 (44%)
Ethnicity	
Non-white	56 (2%)
White	3007 (98%)
Educational attainment	
No qualifications	784 (26%)
Up to degree level	1472 (48%)
Degree level	807 (26%)
Occupational class	
Routine	1204 (39%)
Intermediate	761 (25%)
Managerial/Professional	1097 (36%)
Net non-pension wealth quintile	
1 (poorest)	412 (14%)
2	555 (19%)
3	565 (20%)
4	629 (22%)
5 (richest)	731 (25%)
Marital status	
Single	816 (27%)
Married or living as married	2248 (73%)
Limiting longstanding illness	
Yes	856 (28%)
No	2208 (72%)
ADL or IADL limitations	
Yes	605 (20%)
No	2459 (80%)
Depressive symptoms	
Yes	251 (8%)
No	2813 (92%)
Self-rated general health	
Fair/poor	631 (21%)
Excellent/very good/good	2433 (79%)
Self-rated eyesight	
Fair/poor/blind	252 (8%)
Excellent/very good/good	2812 (92%)
Ever diagnosed with cancer	
Yes	202 (7%)
No	2862 (93%)
Memory	
Mean (SD)	15.1 (3.0)
Verbal fluency	
Mean (SD)	6.2 (2.0)
Memory decline	
Yes	984 (32%)
No	2080 (68%)
Verbal fluency decline	
Yes	1165 (38%)
No	1898 (62%)

Table 10.8 shows the multivariable-adjusted logistic regression model predicting FOBt screening, with health literacy decline as the main predictor and including all covariates that were statistically significant predictors of FOBt screening. The covariates included in the final model were the same as in the above analysis: age, sex, educational attainment, net non-pension wealth, and marital status. Health literacy decline was not associated with uptake of FOBt screening, with OR=1.18 (95% CI: 0.94–1.48) in the first model, adjusted for these sociodemographic characteristics (Table 10.8). Consistent with the previous analysis, where sociodemographic factors were measured at wave 5 (instead of wave 2, as in this analysis), the significant sociodemographic predictors of FOBt screening uptake in the adjusted model were: age (OR=0.85; 95% CI: 0.83–0.86), female sex (OR=1.26; 95% CI: 1.06–1.50), greater net non-pension wealth (OR=1.18; 95% CI: 1.10–1.26 per increasing quintile), and being married or living as married (OR=1.33; 95% CI: 1.10–1.61). Higher educational attainment was positively, but not significantly associated with FOBt uptake (Table 10.8).

When memory and verbal fluency scores at wave 2 were added to the model, the associations between sociodemographic factors and FOBt screening uptake were mostly unaltered (Table 10.8). The OR for health literacy decline was negligibly altered (OR=1.16; 95% CI: 0.92–1.45). The wave 2 measures of memory and verbal fluency were only borderline significantly associated with uptake of FOBt screening from 2010 onwards (OR=1.02; 95% CI: 0.99–1.06 per point increase out of 24 on the memory index and OR=1.01; 95% CI: 0.97–1.06 per point increase out of 9 on the verbal fluency measure; Table 10.8).

When memory decline and verbal fluency decline were added to the model the OR for health literacy decline was again negligibly altered (OR=1.13; 95% CI: 0.90–1.43). The ORs for sociodemographic variables were again mostly unaltered. Adults who did not decline in memory score over the follow-up had borderline statistically significant higher odds of participating in FOBt screening at least once since 2010 than those who declined by one or more point (OR=1.22; 95% CI: 1.00–1.48), while verbal fluency decline was not associated with FOBt screening (OR=1.01; 95% CI: 0.84–1.21; Table 10.8). Memory score at wave 2 became borderline significantly positively associated with FOBt screening in this model, with OR=1.04 (95% CI: 1.00–1.07) per one point increase on the memory index (Table 10.8).

Table 10.8 Adjusted logistic regression predicting FOBt uptake

Characteristic	FOBt screening uptake		
	OR 1 (95% CI)* Yes vs. No	OR 2 (95% CI)† Yes vs. No	OR 3 (95% CI)‡ Yes vs. No
Health literacy decline			
Yes	1.00 (ref)	1.00 (ref)	1.00 (ref)
No	1.18 (0.94, 1.48)	1.16 (0.92, 1.45)	1.13 (0.90, 1.43)
Age			
Mean (SD)	0.85 (0.83, 0.86)	0.85 (0.83, 0.87)	0.85 (0.83, 0.87)
Sex			
Male	1.00 (ref)	1.00 (ref)	1.00 (ref)
Female	1.26 (1.06, 1.50)	1.24 (1.04, 1.47)	1.22 (1.03, 1.46)
Educational attainment			
No qualification	1.00 (ref)	1.00 (ref)	1.00 (ref)
Up to degree level	1.14 (0.93, 1.41)	1.10 (0.88, 1.36)	1.08 (0.87, 1.34)
Degree or equivalent	1.17 (0.92, 1.49)	1.12 (0.87, 1.44)	1.10 (0.86, 1.42)
Net non-pension wealth			
Per increasing quintile	1.18 (1.10, 1.26)	1.17 (1.09, 1.25)	1.16 (1.09, 1.24)
Marital status			
Single	1.00 (ref)	1.00 (ref)	1.00 (ref)
Married or living as married	1.33 (1.10, 1.61)	1.33 (1.10, 1.61)	1.32 (1.09, 1.60)
Memory			
Mean (SD)	-	1.02 (0.99, 1.06)	1.04 (1.00, 1.07)
Verbal fluency			
Mean (SD)	-	1.01 (0.97, 1.06)	1.01 (0.96, 1.06)
Memory decline			
Yes	-	-	1.00 (ref)
No	-	-	1.22 (1.00, 1.48)
Verbal fluency decline			
Yes	-	-	1.00 (ref)
No	-	-	1.01 (0.84, 1.21)

*Adjusted for health literacy, age, sex, educational attainment, net non-pension wealth fifth, and marital status (n=2891)
†Additionally adjusted for memory and verbal fluency (n=2891)
‡Additionally adjusted for memory and verbal fluency decline (n=2890)

10.4 Discussion

In this large study of health literacy, ageing-related health literacy decline, and uptake of FOBt screening through the NHS Bowel Cancer Screening Programme in England, adults with ‘high’ health literacy had nearly 30% greater odds of participating in screening than those with ‘low’ health literacy, independently of sociodemographic factors. This effect was mostly explained by memory and potentially verbal fluency around the time of screening, which were positively associated with screening uptake. Health literacy decline over time was not associated with FOBt screening uptake, and neither was decline in verbal fluency over time or verbal fluency in the years prior to screening. It appears that cognitive function around the time of a screening episode is the more important predictor of screening uptake, compared with cognitive function and decline in the years prior to a screening episode.

A recent study that also used the ELSA dataset aimed to examine whether ‘cognitive ability helps to explain the link between health literacy and screening’ (Gale et al., 2015). The ‘link’ that the study refers to was shown in the manuscript based on this Chapter that was published in the journal *Preventive Medicine* in November 2013 (Appendix 10.1). I had originally decided not to adjust for measures of cognitive function in that manuscript, as I did not want to ‘control out’ any effect of health literacy on cancer screening uptake. Although I did not discuss this issue in the journal article, I had postulated that cognitive function would influence health literacy; therefore adjustment of cognitive function would remove some of health literacy’s effect on cancer screening uptake. I did not care where health literacy ‘came from’ and I wanted to estimate its full unconfounded association with FOBt screening, whether acting as a mediator of other factors or not. Upon further reflection and analysis throughout my PhD and other research, I decided that adjusting for cognitive function measures is important in studies like this, in order to better estimate the independent effects of each of health literacy and cognitive function. However, it is equally important to recognise that objective tests of health literacy inherently also assess cognitive function, so that it becomes difficult to truly separate the two constructs.

In Gale et al.’s study, a general cognitive ability factor was created using the first unrotated principal component of a factor analysis of all of the cognitive function measures included in the ELSA (Gale et al., 2015). The component accounted for 46% of variance in the cognitive function measures (Gale et al., 2015). The authors found weak associations between each of health literacy and generalised cognitive ability with FOBt uptake in their study, with mutually-adjusted ORs of 1.07 (95% CI: 1.10-1.15) per standard deviation in cognitive ability and 1.10 (95% CI: 0.91-1.34) for scoring <4/4 versus scoring 4/4 on the health literacy measure (Gale et al., 2015). They concluded that cognitive ability explains the association between health literacy and cancer screening, and that their estimate for cognitive ability was likely to be an underestimate (Gale et al., 2015). They are likely to be correct at least in their latter conclusion, as 18% of their sample (406/3087) was missing data, mostly on the cognitive function measures, which probably caused attenuation to the null of their point estimates. What was not addressed in their paper was that these missing data also led to a biased point estimate for health literacy: their age- and sex-adjusted OR for health literacy was OR=1.20, 95% CI: 0.99-1.74 (n=2681). I re-ran this model in the full sample that was eligible for their analysis, it was OR=1.37; 95%

CI: 1.15-1.62 (n=3087). Therefore, it is not surprising that adjustment for cognitive ability further attenuated their null-biased point estimate for health literacy.

In my study presented in this chapter, the strongest predictors of FOBt screening uptake were sociodemographic factors, namely younger age within the screening-eligible age range, female sex, higher net non-pension wealth, and being married. These results are consistent with other studies examining the sociodemographic predictors of FOBt screening uptake in England using records from the NHS BCSP (Lo et al., 2015; Logan et al., 2012; von Wagner et al., 2011). However, the interlinked literacy and cognitive barriers to screening are potentially modifiable, while sociodemographic factors are either not or not easily modifiable. Literacy and cognitive skills may therefore represent more feasible intervention targets to increase screening uptake or increase informed decision-making about screening; whether the intervention consists of adapting information materials and communication strategies or efforts to raise literacy and cognitive skills in the older population. Improvement of the NHS communication strategy about FOBt screening would ideally act to reduce literacy-based and cognitive-based inequalities in screening and to improve overall uptake rates in the eligible population.

My findings are consistent with an American study that found lower health literacy, as assessed using a measure of medical vocabulary (the REALM), was associated with lower self-reported FOBt screening uptake (Arnold et al., 2012). However, two other studies found no association between health literacy and FOBt screening uptake (Miller et al., 2007; Peterson et al., 2007). One of these studies was statistically underpowered (Peterson et al., 2007), and the use of the REALM may have limited all three studies: the REALM simply measures medical vocabulary, while the decision to undergo FOBt screening is dependent on a broader range of health literacy skills including reading comprehension, reasoning, and judgement. Higher health literacy has, however, been associated with greater knowledge and more positive attitudes towards colorectal cancer screening (Arnold et al., 2012; Dolan et al., 2004; Miller et al., 2007; N. S. Morris et al., 2013; Peterson et al., 2007).

Consistent with my findings, an American study of a video intervention to communicate colorectal cancer screening information found that adults with low health literacy (REALM-assessed) were less likely to retain cancer screening information in both immediate and one-week delayed memory tests than those with high health literacy (E. A. H. Wilson et al., 2010). This study found that the association between health literacy and retention of cancer screening information was explained by three measures of cognitive functioning: working memory, long term memory, and processing speed (E. A. H. Wilson et al., 2010). These three cognitive function measures explained 46% of the effect of health literacy on screening information retention, and attenuated the point estimate for health literacy to non-significance (β=8.9; 95% CI: -19.6 to 1.8) (E. A. H. Wilson et al., 2010). However, half of the effect of literacy remained unexplained by cognitive measures, indicating that there is also a direct effect of literacy on information retention.

Adults with low health literacy (assessed with the UK-TOFHLA) have also been shown to experience a greater burden of CRC information processing effort compared with those who had high health literacy (von Wagner et al., 2009b). Communication interventions to improve cancer screening uptake rates must therefore be developed to match the cognitive and health literacy levels of the populations they serve. The simple provision of ‘plain-English’ informational materials may not be sufficient, as the current ‘plain-English’ materials provided by the NHS are difficult for people to process and understand (S. G. Smith et al., 2013). ‘Gist’-based information, which simplifies health messages to the simple ‘gist’ of the message, has also been shown to be ineffective in improving screening intentions and uptake among low-literacy adults (S. G. Smith et al., 2015b). Another potential strategy, GP endorsement of screening, was shown in a nationwide randomised controlled trial to slightly improve overall FOBt screening uptake rates in the eligible population, but not to reduce the socioeconomic gradient in uptake (Wardle et al., 2015).

Recent evidence from the American context is useful in identifying ways through which cancer screening can be more appropriately communicated to low literate adults. A randomised trial of a multi-faceted intervention among predominantly uninsured Latino Americans that involved computerised, mailed, automated telephone, and text message reminders, along with a personal telephone call from a screening patient navigator if the test kit was not returned within three months, found that this intervention dramatically increased annual FOBt uptake compared to the usual care of computerised reminders (82.2% vs. 37.7%) (D. W. Baker et al., 2014). The authors found that the initial set of reminders were effective to increase adherence in most cases without the personal telephone call being necessary. Reminders, particularly when delivered in multiple formats, appear to be a cost-effective way to increase screening uptake, particularly among deprived populations, as in this study (D. W. Baker et al., 2014; Krishna, Austin Boren, & Balas, 2009). Another strategy that shows promise to reduce screening inequalities is text-message reminders, implementation and evaluation of which are underway in the BCSP (Hirst et al., 2016).

10.4.1 Limitations

Some of the limitations of this analysis are the same as in Chapters 8 and 9. The ELSA is not perfectly representative of the general screening-eligible population in England. Only 2% of participants in this analysis were non-white, so I did not have adequate statistical power to assess the potential role of ethnicity in predicting FOBt screening uptake. Furthermore, I may have underestimated associations between net non-pension wealth and FOBt screening uptake, as adults with low wealth were under-represented and those with high wealth over-represented due to study attrition. FOBt screening uptake was assessed by self-report rather than from medical records, although the rates of 'ever' uptake since 2006 of 70% (Sample 1) and 71% (Sample 2) are consistent with the 70% rate of 'ever' uptake in the general screening-eligible population of over 62 000 adults in Southern England, according to NHS records (Lo et al., 2015). Self-reported 'ever' FOBt screening uptake has also shown excellent validity against NHS records in a similar sample to this one, showing 94.2% agreement with κ=0.74 (Lo, Waller, Vrinten, Wardle, & von Wagner, 2016). Self-reported FOBt screening uptake has been well-validated against medical records in other studies with sensitivities ranging from 80% to 96% and specificities ranging from 71% to 86% (Baier et al., 2000; N. P. Gordon, Hiatt, & Lampert, 1993; Vernon et al., 2008). I therefore do not expect that the self-report nature of the FOBt uptake measure is a major limitation of this study.

I had originally wanted to examine the role of health literacy in participation in mammogram-based breast cancer screening through the NHS Breast Screening Programme. However, only 112/3201 (3.5%) screening-eligible women aged 50 to 70 years at wave 5 reported having never participated in mammogram screening so I could not analyse this relationship with enough precision to draw conclusions.

10.4.2 Strengths

This analysis examined the roles of health literacy and ageing-related health literacy decline in FOBt screening uptake in the context of the publicly available NHS Bowel

Cancer Screening Programme. It is the first study to address this question in this context. Because overall uptake of the programme remains low in the population and is characterised by social inequalities, my results are valuable for understanding and addressing these problems. Although the measure of health literacy that I used was not validated as a stand-alone measure, it was developed using a framework defining literacy as a functional ability to complete goal-directed tasks (Thorn, 2009). This task represents a health management responsibility commonly faced by older adults that requires reading comprehension and judgement skills; the measure is a more comprehensive measure of functional health literacy skills than simple vocabulary tests such as the REALM, which has been used in previous studies on this topic. I adjusted for important sociodemographic covariates in my analysis, and accounted for the role of cognitive functions that are not directly related to literacy.

10.4.3 Conclusions

Health literacy is positively associated with the uptake of FOBt screening for colorectal cancer, and this association appears to be mostly explained by cognitive function, namely memory, at the time of screening. Ageing-related health literacy decline and verbal fluency decline were not associated with FOBt screening uptake, but memory decline was to a small degree. Overall, literacy and cognitive skills, particularly memory, may together act as functional skills that help adults to engage with and make decisions about whether to participate in FOBt screening.

Future research should examine which aspects of the learning and decision-making processes about cancer screening are affected by literacy or cognitive skills. For example, if memory skills directly affect a person’s ability to remember to complete the test, then subtle reminders and cues can be built into the screening invitation. Or, if literacy skills do pose a barrier, then alternative communication strategies such as patient narratives in opportune settings may be effective in improving uptake. For example, the Cancer Research UK ‘Cancer Awareness Roadshows’ have been shown to be powerful opportunities to educate and shape intentions to engage in cancer prevention and screening among socioeconomically disadvantaged adults who might not access cancer-related information on their own (S. G. Smith, Rendell, George, & Power, 2014). Supporting informed decision-making about cancer screening across all levels of literacy skills in the screening-eligible population should be a priority of the NHS cancer screening programmes.

Chapter 11. Study 5: Health literacy and the long-term maintenance of health promoting lifestyle behaviours[11]

11.1 Background

This chapter investigates the long-term health behavioural implications of low health literacy and health literacy decline during ageing. Health literacy has been inconsistently associated with some health-promoting behaviours among adults in a handful of cross-sectional studies that lack adjustment for physical and cognitive health, which are major limitations in behavioural studies of health literacy (R. J. Adams et al., 2009; I. M. Bennett et al., 2009; Huizinga, Beech, Cavanaugh, Elasy, & Rothman, 2008; Osborn et al., 2011; von Wagner et al., 2007; Wolf et al., 2007). The longitudinal associations between low health literacy, health literacy decline, and health behaviours have never been examined among older adults. These potential relationships are particularly important in the context of ageing, when increasing physical, social, and material changes may pose barriers to achieving good health (Matthews et al., 2014; Steptoe et al., 2015, 2012; Thomas, 2011b). Health literacy skills may become particularly important for the self-management of health and well-being during this time in life. The relative contribution of health literacy to health behaviour, over and above other issues of ageing, is unknown.

Understanding whether health literacy can play a role in promoting the maintenance of health-promoting lifestyle behaviours into older age would be important for public health education efforts to support healthy ageing in the population. The specific health behaviours of interest in this Chapter are therefore those that are consistently and robustly associated with risks of chronic illnesses, such as cardiovascular disease and several cancers, and risk of all-cause mortality: moderate-to-vigorous physical activity (MVPA), fruit and vegetable intake, alcohol consumption, and smoking (Bagnardi et al., 2014; Ford et al., 2011; Friedenreich & Orenstein, 2002; Hamer et al., 2014a; Khaw et al., 2008; Kvaavik et al., 2011; Leitzmann et al., 2007; Ness & Powles, 1997; Rosenkranz et al., 2013; Södergren et al., 2012). As reviewed in Chapter 4, health literacy may influence engagement in these behaviours among older adults through influencing knowledge, motivation, and self-efficacy to engage in behaviour, as well as through influencing the implementation skills necessary to carry out the behaviour (Ajzen, 1991; Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009a). The following subsections review the existing literature on the role of health literacy in health behaviours.

[11] A version of this Chapter is under review at *Am J Prev Med* (Appendix 11.1)

11.1.1 Moderate-to-vigorous physical activity

A body of literature exists on the important roles of self-efficacy and motivation in adherence to physical exercise (Hagger, Chatzisarantis, & Biddle, 2002; McAuley & Blissmer, 2000). Health literacy is thought to fit in as a positive predictor of self-efficacy for physical activity or exercise. In a US-based study of hypertensive patients from federally qualified health centres and a Dutch study of community dwelling older adults, health literacy explained a modest proportion of variance in physical activity behaviour, with self-efficacy for physical activity acting as a mediator of this relationship (Geboers et al., 2014; Osborn et al., 2011). In the US study, health literacy was assessed with the S-TOFHLA and physical activity was measured as weekly frequency of activity (Osborn et al., 2011). In the Dutch study, health literacy was assessed with a 3-item self-report measure from the HLS-EU-Q and physical activity was measured as yes vs. no for compliance with guidelines of at least 30 minutes per day of moderate intensity activity, five days a week (Geboers et al., 2014). Health literacy, as assessed with a measure similar to the S-TOFHLA, was also positively associated with weekly volume (frequency x duration) of physical activity in the Rush Memory and Aging Project of older Americans from the Chicago area (J. S. Bennett et al., 2012). A population-based survey of Australians aged 15 and over found that TOFHLA-assessed health literacy was positively associated with engaging in 150 minutes per week of moderate intensity activity spread across five or more days (R. J. Adams et al., 2013).

In contrast, in a UK study of general population adults aged 16-64 years, health literacy assessed with the UK-TOFHLA was not associated with engaging in physical activity at least once in the past week (von Wagner et al., 2007). Health literacy, as assessed with the S-TOFHLA, was also not associated with weekly frequency of physical activity in an American study of new Medicare enrolees in health plans of a national managed care organisation across four major U.S. cities (Wolf et al., 2007). It is not clear why the results from these five studies are conflicting. Aside from any methodological differences that may have affected results (e.g. different assessments of health literacy and physical activity and differing study populations), there are many structural barriers that people face in taking up or maintaining regular physical activity. Time constraints, having access to appropriate outdoor or gym space and equipment, financial constraints, and social support all play major roles in determining one’s participation in physical activity (Bauman et al., 2012; Dishman, Sallis, & Orenstein, 1984; Koeneman, Verheijden, Chinapaw, & Hopman-Rock, 2011). For older adults, these issues may be magnified, and physical health and functioning also play important roles in determining engagement in physical activity (Koeneman et al., 2011; Steptoe et al., 2015). The sum of these structural and individual factors may or may not override any possible role of health literacy in predicting physical activity behaviour among older adults.

11.1.2 Fruit and vegetable intake

In England, the national public health guidelines on fruit and vegetable intake recommend five daily servings of fruit or vegetables (National Health Service, 2013). Few studies have examined the relationship between health literacy and fruit and vegetable intake. The mechanism of the relationship could be similar to that with physical activity, where health literacy may be a predictor of knowledge and self-efficacy to incorporate more fruit and vegetable servings into one's diet. In the US National Cancer Institute's Health Information and National Trends Survey in the US and Puerto Rico, adults who knew what the public health guidelines for fruit and vegetable intake were and who reported that they regularly search for health information were more likely to also report consuming adequate servings of fruits and vegetables than those who did not know the guidelines and never searched for health information, respectively (Cólón-Ramos et al., 2015). Although this relationship has never been investigated, to the best of my knowledge, adults with high health literacy may be more likely to access, understand, and use information on the dietary importance of fruit and vegetables. For example, the NHS 'Choices' website provides the NHS guidelines on intake and advice on how to incorporate fruits and vegetables into one's diet, and may be differentially accessed by adults according to their health literacy level. Previous research has shown that health information seeking for topics related to cancer is more frequent among adults with high health literacy; this relationship may extend to health information about dietary intake of fruits and vegetables, as well as to the other health behaviours reviewed in this chapter (Kobayashi & Smith, 2015).

A structural barrier that might override any effect of health literacy on dietary intake might be the cost of fruit and vegetables. According to the UK Diet and Nutrition Tool for Evaluation, a 'Health Conscious' diet that incorporates a variety of fruit and vegetables was estimated to cost £6.63 per day, compared with a 'Monotonous Low Quality' diet that includes mostly processed and nutrient poor foods and was estimated to cost £3.29 per day – a difference of £1219.10 per year for one person

(M. A. Morris, Hulme, Clarke, Edwards, & Cade, 2014). If accessing a healthy diet is financially out of reach for a person, then his or her health literacy may not affect dietary intake. Given that retirement often negatively affects financial resources, older adults may more frequently face financial barriers to fruit and vegetable consumption than younger adults (Marmot et al., 2003). Older adults may also often face physical mobility or transport barriers that may inhibit the purchasing or preparation of healthy meals (Matthews et al., 2014). I identified only three studies on the relationship between health literacy and fruit and vegetable intake. The UK study of general population adults, the Australian study of general population adults, and the Dutch study of older adults cited above all found positive associations between health literacy and the consumption of five daily servings of fruit and vegetables (R. J. Adams et al., 2013; Geboers et al., 2014; von Wagner et al., 2007).

11.1.3 Alcohol consumption

The English national public health guidelines on alcohol consumption recommend that women should not regularly drink more than 2-3 units of alcohol per day, and men should not regularly drink more than 3-4 units per day (NHS Choices, 2015). ‘Regularly’ is defined as ‘drinking this amount most days or every day’ (NHS Choices, 2015). Again, health literacy skills would likely act to support access, understanding, and use of these guidelines and other information to make decisions about alcohol consumption. For example, other important information that goes along with the guidelines includes the definition of a unit of alcohol and why the guidelines exist in the first place. The relationship between alcohol consumption and chronic disease risk, particularly cancer risk, is not common knowledge among UK adults and might be better understood by someone with high health literacy who seeks out and uses that information (Isted, Fiorini, & Tillmann, 2015; Redeker, Wardle, Wilder, Hiom, & Miles, 2009). Only two studies on the association between health literacy and alcohol consumption were identified. In the American study of Medicare enrolees above, S-TOFHLA-assessed health literacy was not associated with problematic alcohol consumption (Wolf et al., 2007), while the Australian study of general population adults found that adults with adequate TOFHLA-assessed health literacy were more likely to be defined as at-risk drinkers (defined as >1 drink per day for women and >2 drinks per day for men) (R. J. Adams et al., 2013).

11.1.4 Smoking status

Health literacy skills may be associated with non-smoking through influencing self-efficacy, motivation, and intention to quit or not take up smoking (DiClemente, 1981; Gwaltney, Metrik, Kahler, & Shiffman, 2009; Smit, Fidler, & West, 2011). Knowledge of the health risks of smoking are also associated with smoking cessation, which may be greater among those with high health literacy due to increased ability to access and use relevant information about smoking. In a recent study of middle-aged, predominantly male African American adults, REALM-assessed health literacy was positively associated with a higher perception of personal health risks of smoking and a greater knowledge of what the risks are (Stewart et al., 2013). Health literacy was also negatively associated with nicotine dependence, which is a strong predictor of smoking cessation (Hymowitz et al., 1997; Stewart et al., 2013). However, health literacy was not associated with self-efficacy or intentions to reduce or quit smoking within the next two months in this study (Stewart et al., 2013). REALM-assessed health literacy was also strongly associated with smoking relapse in a trial of a cessation programme, where low health literacy predicted smoking relapse independently of sociodemographic factors and nicotine dependence (Stewart et al., 2014). In the American study of Medicare enrolees, having marginal vs. adequate S-TOFHLA was marginally negatively associated with having quit smoking in a model adjusted for sociodemographic factors and physical functioning (OR=0.70; 95% CI: 0.50-1.00), although it was not associated with ever vs. never smoking (Wolf et al., 2007). Another study that did not adjust for potential confounders found that current smokers more frequently had low health literacy than former or never smokers (Sudore et al., 2006).

In sum, the associations between health literacy and health behaviours appear to be inconsistent across existing studies. The use of different health literacy measures and different methods of assessing health behaviours may contribute to inconsistent results. However, there is some empirical evidence for the roles of self-efficacy and knowledge in explaining the relationships between health literacy and some health behaviours, namely physical activity. All existing studies are cross-sectional, and most have not accounted for cognitive or physical function, which are major limitations in behavioural studies of health literacy, especially among older adults. The longitudinal associations between low health literacy, health literacy decline, and the maintenance of health behaviours over time during ageing have not been previously investigated.

The analyses presented in this chapter aimed to investigate the relationships between low health literacy, health literacy decline, and long-term engagement in four health behaviours (weekly MVPA, five-daily fruit and vegetable servings, non-problematic alcohol consumption, and non-smoking status) over an eight-year follow-up period in the ELSA. I hypothesised that low health literacy and health literacy decline would be associated with long-term engagement in health behaviours independently of cognitive function. I thought that the mechanisms of these associations would involve the uptake and use of information, and would be specific to health literacy. However, I also thought that cognitive function would likely contribute to some degree, due to its influence on health literacy, as demonstrated in Chapter 8. I further hypothesised that ageing-related health literacy decline would be negatively associated with the long-term maintenance of health-promoting lifestyle behaviours. This latter relationship may be more directly caused by declining cognitive function, which I found to have a negative effect on health literacy in Chapter 8.

11.2 Methods

11.2.1 Sample

All ‘core’ ELSA participants who completed data collection at all of waves 1 (2002/03), 2 (2004/05), 3 (2006/07), 4 (2008/09), 5 (2010/11), and 6 (2012/13) without proxy interviews, and who were aged 50-79 years at wave 2 were eligible for inclusion in this analysis. Adults aged 80 years and over were not included in this analysis, as the greater frequency of physical and cognitive limitations might override any effect of health literacy on behaviour in this age group (Rockwood & Mitnitski, 2011). Although the wave 1 data were not directly used in this analysis, participants had to have completed data collection at every single wave from 1 through 6 in order to have the longitudinal population weights available for this analysis (n=4711) (NatCen Social Research, 2014). Therefore, only those who remained in the study at all waves were counted as part of the sample. In total, 4354 participants were age-eligible with non-proxy interviews. Figure 11.1 shows the study eligibility flow.

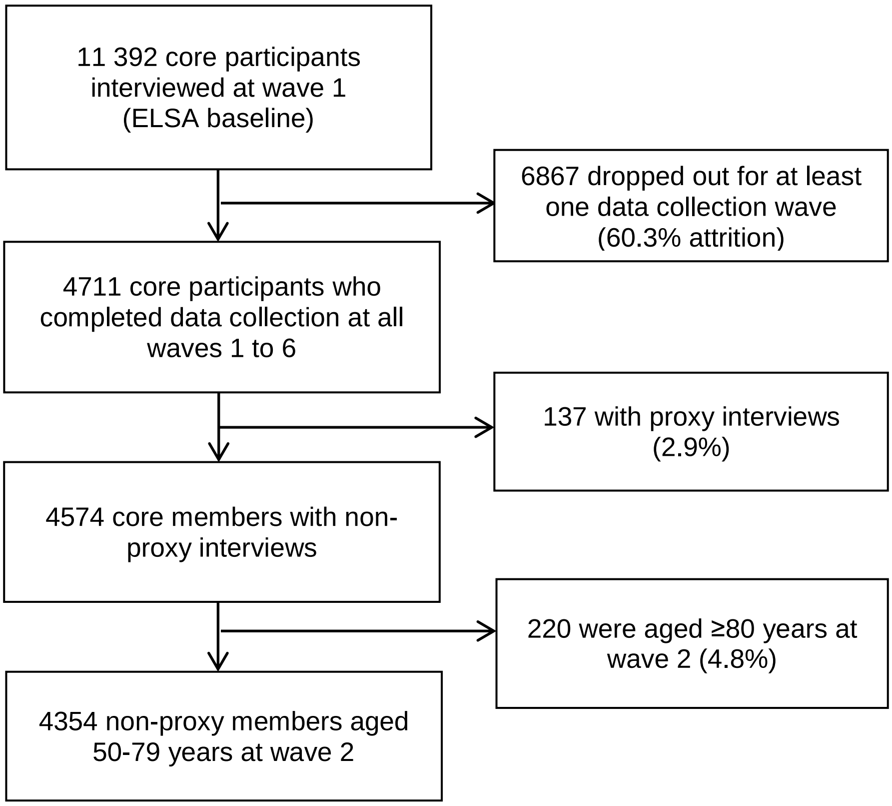

Figure 11.1 Study eligibility flow

11.2.2 Measures

11.2.2.1 Health literacy

Health literacy was measured in the wave 2 and 5 interviews. Health literacy at wave 2 (i.e. baseline for this analysis) was categorised in three levels: ‘low’ (0-2/4 correct), ‘medium’ (3/4 correct), and ‘high’ (4/4 correct). Health literacy decline was defined as a decrease in score of ≥1 point between waves 2 and 5.

11.2.2.2 Leisure-time moderate-to-vigorous physical activity

Leisure-time physical activity was assessed in the main study interview via three questions:

> *‘We would like to know the type and amount of physical activity involved in your daily life. Do you take part in sports or activities that are vigorous [?]’*
>
> *‘And do you take part in sports or activities that are moderately energetic [?]’*
>
> *‘And do you take part in sports or activities that are mildly energetic [?]’*

For each of these questions, the response options read to the participant were: '… more than once a week', 'once a week', 'one to three times a month', and 'hardly ever or never'. Participants were shown a show card with examples of all three intensity levels of physical activity (Appendix 11.2).

At each wave, MVPA was coded dichotomously as engagement in moderate or vigorous intensity activity once per week or more ('active') vs. less than once per week ('inactive'). MVPA, as opposed to mild activity, was selected for analysis because moderate and vigorous intensity activities are protectively associated with health outcomes including cancer, cardiovascular disease, and all-cause mortality (Friedenreich & Orenstein, 2002; Hamer, Lavoie, & Bacon, 2014b; Leitzmann et al., 2007; Samitz, Egger, & Zwahlen, 2011) and are the focus of public health recommendations for physical activity (World Health Organization, 2010). There is little evidence for a protective role of mild intensity activity in chronic health outcomes and all-cause mortality (Friedenreich, Neilson, & Lynch, 2010; I.-M. Lee, 2003; I.-M. Lee & Paffenbarger, 2000).

The final outcome variable was 'yes' vs. 'no' for maintaining weekly MVPA (i.e. being defined as 'active') at all of five time points from wave 2 (2004/05) to wave 6 (2012/13).

11.2.2.3 Fruit and vegetable intake

Fruit and vegetable intake were assessed in the self-completion questionnaire from wave 3 onward. In waves 3 and 4, participants were asked to tick off the various fruit and vegetable servings that they had eaten in the past day. Examples were: 'Salad [cereal bowlfuls]', 'Tablespoons of vegetables [raw, cooked, frozen, or tinned] *include peas and greens. Do not include potatoes*', and, 'Average handfuls of very small fruit, such as grapes, berries'). See Appendix 11.3 for the full assessment from waves 3 and 4. In waves 5 and 6, participants were asked about their fruit and vegetable intake on a typical day in a simpler manner, using only two questions.

The first asked participants:

> *'How many portions of vegetables – excluding potatoes – do you eat on a typical day? If none, please enter 0'*

The following guidance was given about portion sizes:

‘A serving or portion of vegetables means three heaped tablespoons of green or root vegetables such as carrots, parsnips, small vegetables like peas, baked beans or sweet corn, or a medium bowl of salad (lettuce, tomatoes, etc.)’

The second question asked participants,

‘How many portions of fruit – of any kind – do you eat on a typical day? If none, please enter 0’

The following guidance was given about portion sizes:

‘A portion of fruit is an apple or banana, a small bowl of grapes, or three tablespoons of tinned or stewed fruit. If you drink fruit juice, you can count one glass per day, but additional glasses of fruit juice do not count as additional portions’

Participants were asked to write in the portion(s) in a blank box. Appendix 11.3 also shows the full fruit and vegetable intake assessment from waves 5 and 6. Daily fruit and vegetable intake was classified according to the evidence-based NHS “5 A DAY” recommendation of five daily servings of fruit and vegetables (National Health Service, 2013). At each wave, fruit and vegetable intake was coded dichotomously as meeting or not meeting this recommendation.

The final outcome variable was ‘yes’ vs. ‘no’ for consuming 5 servings of fruit and vegetables per day at all of four time points from wave 3 (2006/07) to wave 6 (2012/13).

11.2.2.4 Alcohol consumption

Alcohol consumption was assessed in the self-completion questionnaire. Participants were given the following item:

‘Thinking now about all kinds of drinks, how often have you had an alcoholic drink of any kind during the last 12 months?’

Participants were instructed to tick one box, with the response options of ‘Almost every day’, ‘Five or six days a week’, ‘Three or four days a week’, ‘Once or twice a week’, ‘Once or twice a month’, ‘Once every couple of months”, ‘Once or twice a year’, or ‘Not at all in the last 12 months’. The NHS guidelines for daily alcohol consumption are that women should not regularly drink more than 2-3 units of alcohol per day, and men should not regularly drink more than 3-4 units per day

(NHS Choices, 2015). In this context, ‘regularly’ is defined as ‘drinking this amount most days or every day’ (NHS Choices, 2015). Therefore, at each wave, those who reported drinking ‘Almost every day’ were classified as having ‘problematic’ alcohol consumption. Otherwise, they were classified as having ‘non-problematic’ alcohol consumption.

Alcohol consumption was also measured as frequency in the past 7 days and total volume in the past 7 days. In large population-based studies like the ELSA, past year alcohol consumption is generally considered to be more representative of regular drinking behaviour than is past week alcohol consumption (Dawson, 2003); therefore the past year assessment was used.

The final outcome variable was ‘yes’ vs. ‘no’ for non-problematic weekly alcohol consumption at all of five time points from wave 2 (2004/05) to wave 6 (2012/13). Participants who reported drinking ‘almost every day’ at one or more time points were classified as ‘problematic drinkers’ (i.e. ‘no’ for ‘non-problematic drinking’ across the follow-up).

11.2.2.5 Smoking

Smoking status was assessed at each wave in the study interview. In the wave 1 study interview, participants were asked, ‘Have you ever smoked cigarettes?’ The response to this item was combined with responses to the item ‘Do you smoke cigarettes at all nowadays?’ at waves 2 through 6. Participants were classified as being ‘never’ smokers (reported ‘no’ to ever smoking and ‘no’ to smoking nowadays at all waves from 2 through 6), ‘former’ smokers (reported ‘yes’ to having ever smoked cigarettes, but ‘no’ to smoking nowadays through all of waves 2 through 6), and ‘current/transitioning’ smokers (reported ‘yes’ or ‘no’ to having ever smoked cigarettes, and ‘yes’ to smoking nowadays at any of waves 2 through 6). For simplicity, the ‘never’ and ‘former’ categories were collapsed to represent non-smoking over the study period, although they were expanded again in a sensitivity analysis (described in more depth below in Section 11.2.3).

The final outcome variable was ‘yes’ vs. ‘no’ for non-smoking at all of five time points from wave 2 (2004-05) to wave 6 (2012-13). Those who reported smoking at any one or more time points were defined as smokers (i.e. ‘no’ for ‘non-smoking’ across the follow-up).

11.2.2.6 Covariates

Covariates that were known to be associated with health literacy or longitudinal trajectories of health behaviours in the ELSA were: age (continuous), sex (male; female), ethnic minority status (white; non-white), educational attainment (degree-level; up to degree-level; no qualifications), net non-pension wealth (calculated in quintiles stratified at age 65 to account for the effect of retirement on wealth), marital status (married or living as married; single, divorced, or widowed), working status (yes; no), access to a car when needed (yes; no), self-rated health (excellent/very good/good; fair/poor), having a limitation in one or more instrumental activity of daily living (IADL; yes; no), having a limiting long-standing illness (yes; no), presence of depressive symptoms, defined as scoring >4 on the 8-item Centre for Epidemiological Studies Depression Scale (yes; no), and the memory and verbal fluency variables (at baseline and decline) used in Chapter 8 (Matthews et al., 2014). All covariates, with the exception of cognitive decline variables, were assessed in the wave 2 study interview.

11.2.2.7 Timing of measurements

Table 11.1 below summarises the timing of the measurements for all variables, between waves 2 and 6 of the ELSA.

Table 11.1 **Timing of measurements for the analyses presented in this chapter**

Variables	Wave 2 (2004-05)	Wave 3 (2006-07)	Wave 4 (2008-09)	Wave 5 (2010-11)	Wave 6 (2012-13)
Baseline health literacy	X				
Health literacy decline	X			X	
MVPA	X	X	X	X	X
Fruit & vegetable intake		X	X	X	X
Alcohol consumption	X	X	X	X	X
Smoking status	X	X	X	X	X
Covariates	X				
Baseline cognitive function	X				
Cognitive decline	X			X	

11.2.3 Statistical analysis

The characteristics of the sample were described using means and standard deviations for continuous variables and frequency counts for categorical variables. The frequencies of long-term engagement in health behaviours (yes vs. no) according to baseline health literacy, health literacy decline, and sociodemographic, health-related, and cognitive function and decline variables were calculated and analysed bivariately using χ^2 tests. Population-weighted logistic regression models were used to estimate the relationships between baseline health literacy, health literacy decline, and long-term engagement in health behaviours (i.e. weekly MVPA, five-daily fruit and vegetable servings, non-problematic alcohol consumption, and non-smoking). Separate models were built for each of the health behaviours, with baseline health literacy and health literacy decline included in the same regression models so that they were mutually adjusted for.

All *a priori*-identified sociodemographic, health-related, and cognitive variables were included in initial models. Covariates that were statistically non-significant in each model were removed (i.e. $p \geq 0.05$ for association with a given health behaviour) if their deletion did not result in a ≥10% change in the OR between health literacy and the health behaviour in question (Rothman & Greenland, 2008). The exceptions were for age, gender, education, and cognitive function and decline variables, which were forced into all models. Net non-pension wealth quintile was added as continuous variable into all models, as it was positively linearly associated with each of the health behaviour outcome variables. The cross-sectional baseline health behaviours, which could have been considered at wave 1 (2002-03), two years prior to this analysis, or at wave 2 (2004-05), the 'true' baseline of this analysis, were not adjusted for in statistical models to prevent the baseline adjustment bias (Glymour et al., 2005). In this instance, conditioning on any of the cross-sectional baseline health behaviours is likely to introduce spurious correlations between baseline health literacy and the longitudinal health behaviour variables (Glymour et al., 2005). Changes in physical health from baseline were also not adjusted for, I consider them to probably lie on the causal pathway between low health literacy and health behaviours, given the known relationships between health literacy and physical health/function, and physical health/function and health behaviour (Berkman et al., 2011; Rosenkranz et al., 2013; S. G. Smith et al., 2015a; Södergren et al., 2012). Unadjusted and fully adjusted population-weighted odds ratios for all statistically significant predictors of each of the four health behaviours are presented.

Three sensitivity analyses were performed. Non-smokers were divided into 'former' and 'never' smokers, and the smoking analysis was re-run using adjusted multinomial logistic regression with the three-category smoking variable as the outcome ('former' smokers who never smoked over the follow-up; 'never' smokers who never smoked over the follow-up; and 'current/transitioning' smokers who smoked in at least time point over the follow-up). The model for non-problematic alcohol consumption was re-run separating adults who abstained throughout the follow-up into a third outcome category, giving ‘abstainers’ at any time point over the follow-up, ‘non-problematic drinkers’ who always drank but at a non-problematic frequency, and ‘problematic drinkers’ who drank ‘almost every day’ at one or more time point. This was done because complete abstainers from alcohol might have different health profiles (and potentially different levels of health literacy) than people who drink even a small amount, given that alcohol consumption is typically a socially normative behaviour for healthy adults (Fat, Cable, Marmot, & Shelton, 2014). Next, the definition of maintaining a healthy behaviour over the follow-up was relaxed by defining ≥three time points, regardless of timing, as maintaining engagement.

Longitudinal population weights were applied to all regression models to account for any potential bias due to differential study non-response and attrition and missing data. All statistical tests were two-sided and performed at the 95% confidence level using StataSE 13.1 (StataCorp, College Station, TX).

11.3 Results

11.3.1 Missing data

At wave 2, 4278/4354 (98.3%) participants completed the health literacy assessment. As in previous chapters, non-completion was due to refusal (n=6), sight difficulties (n=19), health problems (n=7), or other reason (n=44). At wave 5, 4224/4354 (97.0%) completed the health literacy assessment. Non-completion was due to refusal (n=20), sight difficulties (n=45), health problems (n=16), reading problems (n=21), and other reasons including being too tired, not knowing what to do, or being distracted (n=28). As in Chapter 10, refusals were excluded and those who were unable to answer the health literacy questions were included and coded as scoring 0/4 on the measure, as they would likely perform with low health literacy in real-life settings. Thus, 4348/4354 (99%) participants had health literacy data at wave 2 and 4344/4354 (99%) had health literacy at wave 5, with 4328/4354 (99%) at both waves.

No data were missing for physical activity or smoking; these variables were assessed in the in-person study interviews, which had low rates of incomplete data. Data on fruit and vegetable intake were missing for 345/4354 (7.9%) participants who did not return the self-completion questionnaire at wave 3, 347/4354 (8.0%) who did not return it at wave 4, 213/4354 (4.9%) who did not return it at wave 5, and 299/4354 (6.9%) who did not return it at wave 6. The sum of these missing responses led to 824/4354 (18.9%) of responses missing for fruit and vegetable intake. The same data were missing for alcohol consumption as for fruit and vegetable intake, with the addition of 278/4354 (6.4%) participants who did not return the self-completion questionnaire at wave 2.

For the covariates, 1/4354 participants was missing data on ethnicity, 1/4354 on education, 216/4354 on net non-pension wealth quintile, 1/4354 on access to a car when needed, 2/4354 on self-rated health, 1/4354 on depressive symptoms, 13/4354 on memory at wave 2, 16/4354 on memory at wave 5, 10/4354 on verbal fluency at wave 2, and 19/4354 on verbal fluency at wave 5. All of these missing data percentages were less than 1%, with the exception of net non-pension wealth, which was missing 5% of data.

After accounting for all missing data on health literacy and covariates, 4098/4354 (94%) participants remained in the sample. Following removal of missing cases for each of the health behaviours, the final analytical sample sizes for the logistic regression models were: 4095/4354 (94%; MVPA); 3367/4354 (77%; fruit and vegetable intake); 3277/4354 (75%; alcohol consumption); and, 4098/4354 (94%; smoking).

11.3.2 Sample characteristics

Table 11.2 shows the sociodemographic and health-related characteristics of the ELSA sample included in this sample. The mean age was 63.4 (SD 7.3) years. Just over half of participants were female (2285/4098; 56%), and only 2% were non-white (69/4098). One-quarter had degree level education (1034/4098; 25%), just under half had up to degree education (1884/4098; 46%), and just under one-third had no qualification (1180/4098; 29%). The wealth quintiles were skewed towards wealthier participants (623/4098 [15%] in the poorest quintile and 998/4098 [24%] in the wealthiest quintile). Nearly three-quarters were married or living as married (2993/4098; 73%), 60% were not working (2458/4098), and most had access to a car when needed (3639/4098; 89%). Most had excellent, very good, or good self-rated health (3290/4098; 80%), no limiting long-standing illness (2958/4098; 72%), no IADL limitations (3239/4098; 79%), and no presence of depressive symptoms (3754/4098; 92%).

Table 11.2 Characteristics of the sample, n=4098

Characteristic	N (%)
Age	
Mean (SD)	63.4 (7.3)
Sex	
Female	2285 (56%)
Male	1813 (44%)
Ethnicity	
Non-white	69 (2%)
White	4029 (98%)
Educational attainment	
No qualifications	1180 (29%)
Up to degree level	1884 (46%)
Degree level	1034 (25%)
Net non-pension wealth quintile	
1 (poorest)	623 (15%)
2	762 (19%)
3	844 (21%)
4	871 (21%)
5 (richest)	998 (24%)
Marital status	
Single	1105 (27%)
Married or living as married	2993 (73%)
Working status	
No	2458 (60%)
Yes	1640 (40%)
Access to a car when needed	
No	459 (11%)
Yes	3639 (89%)
Self-rated general health	
Fair/poor	808 (20%)
Excellent/good/very good	3290 (80%)
Limiting long-standing illness	
Yes	1140 (28%)
No	2958 (72%)
IADL limitations	
Yes	859 (21%)
No	3239 (79%)
Presence of depressive symptoms	
Yes	344 (8%)
No	3754 (92%)

Table 11.3 shows the distribution of health literacy and cognitive function variables in this sample. At baseline (wave 2), 377/4098 (9%) had low health literacy (≤2/4 items correct), 749/4098 (18%) had medium health literacy (3/4 items correct), and 2972/4098 (73%) had high health literacy. Similar to the ELSA samples used in Chapters 8 and 9, 745/4098 (18%) experienced health literacy decline over the follow-up (waves 2 to 6). The mean baseline memory score (the number of words recalled out of 20, plus stating the correct day of the week, date, month, and year, out of 4) was 14.7 (SD 3.2). The mean baseline verbal fluency score (out of 9, corresponding to the categories of number of animals names) was 5.9 (SD 2.1),

corresponding to 18-19 animals (category 5) or 20-21 animals (category 6). One-third of participants declined in memory score between waves 2 and 6 (1410/4098; 34%), and 40% declined in verbal fluency score (1632/4098).

Table 11.3 Health literacy and cognitive function of the sample

	N (%)
Baseline health literacy	
Low	377 (9%)
Medium	749 (18%)
High	2972 (73%)
Health literacy decline	
Yes	745 (18%)
No	3353 (82%)
Baseline memory (out of 24)	
Mean (SD)	14.7 (3.2)
Baseline verbal fluency	
Mean (SD)	5.9 (2.1)
Memory decline	
Yes	2688 (66%)
No	1410 (34%)
Verbal fluency decline	
Yes	2466 (60%)
No	1632 (40%)

11.3.3 Sample characteristics according to health behaviours

Table 11.4 shows the sample characteristics according to the maintenance of four health behaviours from waves 2 to 6. The distributions of the health behaviours were: weekly MVPA (2251/4095; 55%), five-daily fruit and vegetable intake (783/3367; 23%), non-problematic drinking (2370/3277; 72%), and non-smoking (3556/4098; 87%). The long-term maintenance of weekly MVPA significantly differed across levels of all variables. Those who consistently reported weekly MVPA tended to be younger, male, white, more highly educated, in a higher net wealth quintile, married, still in work, had access to a car when needed, and were in good health according to all health measures (Table 11.4). Those who consistently reported five-daily fruit and vegetable intake tended to be female, more highly educated, in a higher net wealth quintile, had access to a car when needed, and had good self-rated health and no IADL limitations. There were no differences in fruit and vegetable intake according to age, ethnicity, marital status, working status, limiting long-standing illness, or depressive symptoms (Table 11.4). Those who reported non-problematic alcohol consumption (i.e. drinking less than ‘almost every day’ at every data collection wave) tended to female, less highly educated, in a lower net wealth quintile, single, had no access to a car when needed, and were in worse health according to all health measures (Table 11.4). There were no differences in alcohol consumption according to age, ethnicity, or working status. Those who consistently reported not smoking across the study period were older, more highly educated, in a higher net wealth quintile, married, no longer in work, and in good health according to all health measures (Table 11.4). Long term non-smoking status did not differ according to sex or ethnicity (Table 11.4).

Table 11.4 Frequencies of long-term health behaviours according to sociodemographic and health-related characteristics, waves 2 to 6

Characteristic	Weekly MVPA (Yes; 2251/4095; 55%)	Five-daily fruit & veg (Yes; 783/3367; 23%)	Non-problematic drinking (Yes; 2370/3277; 72%)	Non-smoking (Yes; 3556/4098; 87%)
Age				
Mean (SD) for yes vs. no	62.0 (7.2) vs. 65.2 (7.8)	62.9 (6.8) vs. 63.3 (7.2)	63.2 (7.2) vs. 63.3 (6.9)	63.7 (7.3) vs. 61.4 (6.7)
p-value	<0.0001	0.11	0.77	<0.0001
Sex				
Female	1140 (50%)	503 (27%)	1421 (78%)	1984 (87%)
Male	1111 (61%)	280 (19%)	949 (65%)	1572 (87%)
p-value	<0.0001	<0.0001	<0.0001	0.91
Ethnicity				
Non-white	28 (41%)	6 (17%)	26 (87%)	60 (87%)
White	2223 (55%)	777 (23%)	2344 (72%)	3496 (87%)
p-value	0.015	0.34	0.08	0.96
Educational attainment				
No qualifications	455 (39%)	172 (19%)	719 (82%)	968 (82%)
Up to degree level	1105 (59%)	389 (25%)	1092 (71%)	1651 (88%)
Degree level	691 (67%)	222 (25%)	559 (65%)	937 (91%)
p-value	<0.0001	0.002	<0.0001	<0.0001
Net non-pension wealth quintile				
1 (poorest)	211 (34%)	77 (17%)	361 (81%)	452 (73%)
2	353 (46%)	125 (20%)	487 (83%)	632 (83%)
3	455 (54%)	153 (22%)	528 (78%)	747 (89%)
4	536 (62%)	176 (24%)	509 (70%)	802 (92%)
5 (richest)	696 (70%)	252 (29%)	485 (58%)	923 (92%)
p-value	<0.0001	<0.0001	<0.0001	<0.0001
Marital status				
Single	486 (44%)	180 (22%)	606 (78%)	899 (81%)
Married or living as married	1765 (59%)	603 (24%)	1764 (71%)	2657 (89%)
p-value	<0.0001	0.27	<0.0001	<0.0001
Working status				
No	1155 (47%)	483 (24%)	1441 (73%)	2158 (88%)
Yes	1096 (67%)	300 (22%)	929 (71%)	1398 (85%)
p-value	<0.0001	0.29	0.29	0.02
Access to a car when needed				

No	145 (32%)	59 (18%)	250 (84%)	360 (78%)
Yes	2106 (58%)	724 (24%)	2120 (71%)	3196 (88%)
p-value	<0.0001	0.03	<0.0001	<0.0001
Self-rated general health				
Fair/Poor	234 (29%)	107 (17%)	486 (81%)	642 (79%)
Excellent/Good/Very good	2017 (61%)	676 (25%)	1884 (70%)	2914 (89%)
p-value	<0.0001	<0.0001	<0.0001	<0.0001
Limiting long-standing illness				
Yes	372 (33%)	197 (22%)	671 (76%)	960 (84%)
No	1879 (64%)	586 (24%)	1699 (71%)	2596 (88%)
p-value	<0.0001	0.21	0.002	0.003
IADL limitations				
Yes	250 (29%)	136 (20%)	508 (77%)	717 (83%)
No	2001 (62%)	647 (24%)	1862 (71%)	2839 (88%)
p-value	<0.0001	0.03	0.002	0.001
Presence of depressive symptoms				
Yes	136 (40%)	52 (20%)	206 (80%)	279 (81%)
No	2115 (56%)	731 (24%)	2164 (72%)	3277 (87%)
p-value	<0.0001	0.09	0.003	0.001

11.3.4 Health literacy and cognitive function according to health behaviours

Table 11.5 shows the health literacy and cognitive variables according to the long-term maintenance of the four health behaviours. Weekly MVPA was strongly graded by baseline health literacy, with 35% (130/377) of those with low health literacy, 46% (347/749) with medium health literacy, and 60% (1774/2972) with high health literacy consistently reporting engaging in weekly MVPA at all data collection waves over the study follow-up (p<0.0001). Similarly, 43% (322/745) of participants who experienced health literacy decline compared with 58% (1929/3353) of those who did not decline in health literacy consistently reported weekly MVPA over the study follow-up (p<0.0001). Mean baseline memory and verbal fluency scores were higher for those who engaged in long-term MVPA, and those who did not cognitively decline more frequently engaged in long-term MVPA (p<0.0001 for all; Table 11.5).

Consumption of five daily fruit and vegetable servings over the follow-up was non-differential by baseline health literacy, although those who did not decline in health literacy more frequently reported five daily servings consistently across the follow-up (24% [670/3353] vs. 20% [113/745]; p=0.03). Mean baseline memory and verbal fluency scores were higher for those who consistently reported five daily fruit and vegetable servings, while there was no difference according to cognitive decline.

Non-problematic drinking (i.e. drinking less than 'almost every day') was graded by baseline health literacy, but not in the expected direction, as 77% (196/377) of those with low health literacy, 76% (446/749) with medium health literacy, and 71% (1728/2972) with high health literacy consistently reported non-problematic drinking (p=0.006; Table 11.5). Similarly, 76% of participants who experienced health literacy decline compared with 72% of those who did not decline in health literacy reported non-problematic drinking consistently over the follow-up (p=0.03). Mean baseline memory and verbal fluency scores were lower for those who consistently reported non-problematic drinking; there was no difference according to cognitive decline (Table 11.5).

Non-smoking status was slightly graded by health literacy, where 83% (312/377) of those with low health literacy, 86% (642/749) with medium health literacy, and 88% (2602/2972) with high health literacy consistently reporting non-smoking across the follow-up (p=0.02; Table 11.5). There was no difference in smoking according to health literacy decline or cognitive decline, although consistent non-smokers had higher baseline verbal fluency than those who smoked at any point (p=0.01).

Table 11.5 Frequencies of long-term health behaviours according to health literacy and cognitive function variables, waves 2 to 6

Characteristic	Weekly MVPA (Yes; 2251/4095; 55%)	Five-daily fruit & veg (Yes; 783/3367; 23%)	Non-problematic drinking (Yes; 2370/3277; 71%)	Non-smoking (Yes; 3556/4098; 87%)
Baseline health literacy				
Low	130 (35%)	55 (21%)	196 (77%)	312 (83%)
Medium	347 (46%)	141 (23%)	446 (76%)	642 (86%)
High	1774 (60%)	587 (24%)	1728 (71%)	2602 (88%)
p-value	<0.0001	0.60	0.006	0.02
Health literacy decline				
Yes	322 (43%)	113 (20%)	427 (76%)	632 (85%)
No	1929 (58%)	670 (24%)	1943 (72%)	2924 (87%)
p-value	<0.0001	0.03	0.03	0.08
Baseline memory				
Mean (SD) for yes vs. no	15.3 (0.06) vs. 14.1 (0.08)	15.2 (3.0) vs. 14.8 (3.1)	14.8 (3.1) vs. 15.3 (3.1)	14.7 (3.2) vs. 14.6 (3.3)
p-value	<0.0001	0.0006	<0.0001	0.56
Baseline verbal fluency				
Mean (SD) for yes vs. no	6.3 (0.04) vs. 5.5 (2.1)	6.2 (2.0) vs. 6.0 (2.0)	5.9 (2.0) vs. 6.4 (2.0)	6.0 (2.0) vs. 5.7 (2.1)
p-value	<0.0001	0.008	<0.0001	0.01
Memory decline				
Yes	706 (50%)	255 (22%)	811 (73%)	1210 (86%)
No	1545 (58%)	528 (24%)	1559 (72%)	2346 (87%)
p-value	<0.0001	0.45	0.43	0.19
Verbal fluency decline				
Yes	836 (51%)	288 (22%)	947 (72%)	1409 (86%)
No	1415 (57%)	495 (24%)	1423 (72%)	2147 (87%)
p-value	<0.0001	0.05	0.98	0.50

11.3.5 Multivariable modelling of health behaviours

Table 11.6 shows the unadjusted and fully adjusted population-weighted odds ratios for all statistically significant predictors of long-term weekly MVPA (yes vs. no). Adults with high baseline health literacy had higher odds of reporting long-term weekly MVPA (OR=1.39; 95% CI: 1.04–1.84 vs. low), as did those who did not decline in health literacy (OR=1.34; 95% CI: 1.10–1.63 vs. those who did decline). Older age was inversely associated with long-term weekly MVPA (Table 11.6). Men, those who were more highly educated, wealthier, healthier according to all three health measures, and who had higher baseline cognitive function and did not experience cognitive decline all had higher odds of maintaining weekly MVPA.

Table 11.6 Population-weighted logistic regression predicting weekly MVPA, waves 2 to 6, n=4095

Predictors	Weekly MVPA Unadjusted OR (95% CI)	Weekly MVPA Fully adjusted OR (95% CI)
Baseline health literacy		
Low	1.00 (ref)	1.00 (ref)
Medium	1.68 (1.28, 2.21)	1.21 (0.89, 1.64)
High	2.73 (2.15, 3.47)	1.39 (1.04, 1.84)
Health literacy decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.79 (1.52, 2.12)	1.34 (1.10, 1.63)
Age		
Per year increase	0.94 (0.93, 0.95)	0.95 (0.94, 0.96)
Sex		
Female	1.00 (ref)	1.00 (ref)
Male	1.60 (1.41, 1.83)	1.46 (1.26, 1.70)
Educational attainment		
No qualifications	1.00 (ref)	1.00 (ref)
Up to degree level	2.32 (1.99, 2.71)	1.18 (0.98, 1.42)
Degree level	3.18 (2.66, 3.82)	1.58 (1.28, 1.96)
Net non-pension wealth		
Per increasing quintile	1.44 (1.38, 1.52)	1.28 (1.21, 1.36)
Self-rated general health		
Fair/Poor	1.00 (ref)	1.00 (ref)
Excellent/Good/Very good	4.11 (3.45, 4.89)	1.68 (1.36, 2.09)
Limiting long-standing illness		
Yes	1.00 (ref)	1.00 (ref)
No	3.84 (3.30, 4.46)	2.18 (1.80, 2.62)
IADL limitations		
Yes	1.00 (ref)	1.00 (ref)
No	3.99 (3.36, 4.73)	1.72 (1.41, 2.10)
Baseline memory		
Per point increase	1.14 (1.11, 1.16)	1.04 (1.01, 1.07)
Baseline verbal fluency		
Per point increase	2.21 (1.17, 1.25)	1.05 (1.01, 1.09)
Memory decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.37 (1.19, 1.56)	1.30 (1.10, 1.54)
Verbal fluency decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.26 (1.11, 1.44)	1.20 (1.02, 1.40)

Table 11.7 shows the unadjusted and fully adjusted population-weighted odds ratios for all statistically significant predictors of long-term five-daily fruit and vegetable intake (yes vs. no). Baseline health literacy and health literacy decline were not associated with long-term fruit and vegetable intake after accounting for covariates. Memory was not associated with long-term fruit and vegetable intake, although baseline verbal fluency and verbal fluency decline were positively associated with intake (baseline: OR=1.04; 95% CI: 0.99–1.09 per point increase; decline: OR=1.23; 95% CI: 1.02–1.48 for no vs yes). Men and adults in work at baseline had lower odds of consistently reporting consuming five daily fruit and vegetable servings, while more highly educated, wealthier, and self-rated healthier adults had higher odds of reporting consuming five daily servings (Table 11.7).

Table 11.7 Population-weighted logistic regression predicting five daily fruit & veg intake, waves 2 to 6, n=3367

Predictors	Five daily fruit & veg Unadjusted OR (95% CI)	Five daily fruit & veg Fully adjusted OR (95% CI)
Baseline health literacy		
Low	1.00 (ref)	1.00 (ref)
Medium	1.26 (0.88, 1.82)	1.08 (0.75, 1.57)
High	1.28 (0.93, 1.77)	0.97 (0.68, 1.36)
Health literacy decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.30 (1.03, 1.64)	1.11 (0.88, 1.42)
Age		
Per year increase	0.99 (0.98, 1.00)	0.99 (0.97, 1.00)
Sex		
Female	1.00 (ref)	1.00 (ref)
Male	0.64 (0.54, 0.77)	0.61 (0.51, 0.73)
Educational attainment		
No qualifications	1.00 (ref)	1.00 (ref)
Up to degree level	1.39 (1.14, 1.72)	1.24 (0.98, 1.56)
Degree level	1.50 (1.19, 1.89)	1.26 (0.97, 1.64)
Net non-pension wealth		
Per increasing quintile	1.20 (1.13, 1.28)	1.16 (1.08, 1.24)
Working status		
No	1.00 (ref)	1.00 (ref)
Yes	0.94 (0.80, 1.12)	0.81 (0.65, 0.99)
Self-rated general health		
Fair/Poor	1.00 (ref)	1.00 (ref)
Excellent/Good/Very good	1.53 (1.21, 1.93)	1.36 (1.06, 1.74)
Baseline memory		
Per point increase	1.05 (1.02, 1.08)	1.00 (0.97, 1.04)
Baseline verbal fluency		
Per point increase	1.06 (1.02, 1.11)	1.04 (0.99, 1.09)
Memory decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.05 (0.88, 1.25)	1.02 (0.84, 1.23)
Verbal fluency decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.20 (1.01, 1.42)	1.23 (1.02, 1.48)

Table 11.8 shows the unadjusted and fully adjusted population-weighted odds ratios for all statistically significant predictors of long-term non-problematic alcohol consumption, defined as drinking less than 'almost every day' (yes vs. no). Baseline health literacy and health literacy decline were not associated with long-term non-problematic drinking after accounting for covariates. Men, and adults from white ethnic backgrounds, with higher educational attainment, higher wealth, and better self-rated health were less likely to report non-problematic drinking consistently over the follow-up, that is, they were more likely to report drinking 'almost every day' at any point over the follow-up (Table 11.8). Those with higher baseline memory and verbal fluency scores were borderline significantly less likely to report non-problematic drinking, and cognitive decline was not associated with long-term non-problematic drinking (Table 11.8).

Table 11.8 Population-weighted logistic regression predicting non-problematic drinking, waves 2 to 6, n=3277

Predictors	Non-problematic drinking Unadjusted OR (95% CI)	Non-problematic drinking Fully adjusted OR (95% CI)
Baseline health literacy		
Low	1.00 (ref)	1.00 (ref)
Medium	0.91 (0.63, 1.31)	1.09 (0.74, 1.60)
High	0.70 (0.50, 0.96)	1.05 (0.74, 1.48)
Health literacy decline		
Yes	1.00 (ref)	1.00 (ref)
No	0.78 (0.63, 0.97)	0.89 (0.70, 1.12)
Age		
Per year increase	1.00 (0.99, 1.01)	0.99 (0.98, 1.00)
Sex		
Female	1.00 (ref)	1.00 (ref)
Male	0.53 (0.45, 0.62)	0.54 (0.45, 0.64)
Ethnicity		
Non-white	1.00 (ref)	1.00 (ref)
White	0.28 (0.09, 0.82)	0.25 (0.08, 0.76)
Educational attainment		
No qualifications	1.00 (ref)	1.00 (ref)
Up to degree level	0.55 (0.44, 0.68)	0.78 (0.62, 0.99)
Degree level	0.43 (0.34, 0.55)	0.65 (0.51, 0.84)
Net non-pension wealth		
Per increasing quintile	0.73 (0.68, 0.78)	0.78 (0.73, 0.84)
Self-rated general health		
Fair/poor	1.00 (ref)	1.00 (ref)
Excellent/good/very good	0.57 (0.45, 0.72)	0.79 (0.61, 1.00)
Baseline memory		
Per point increase	0.95 (0.92, 0.97)	0.97 (0.93, 1.00)
Baseline verbal fluency		
Per point increase	0.89 (0.86, 0.93)	0.95 (0.91, 1.00)
Memory decline		
Yes	1.00 (ref)	1.00 (ref)
No	0.94 (0.80, 1.12)	0.91 (0.75, 1.10)
Verbal fluency decline		
Yes	1.00 (ref)	1.00 (ref)
No	0.99 (0.84, 1.16)	0.95 (0.79, 1.13)

Table 11.9 shows the unadjusted and fully adjusted population-weighted odds ratios for all statistically significant predictors of long-term non-smoking (yes vs. no). Baseline health literacy and health literacy decline were not associated with long-term non-smoking after accounting for covariates. Older adults, and those with higher education, higher wealth, who were married, and with better self-rated health were all more likely to consistently report not smoking over the follow-up (Table 11.9). Cognitive function and cognitive decline were not associated with long-term non-smoking status (Table 11.9).

Table 11.9 Population-weighted adjusted logistic regression predicting non-smoking, waves 2 to 6, n=4098

Predictors	Non-smoking Unadjusted OR (95% CI)	Non-smoking Fully adjusted OR (95% CI)
Baseline health literacy		
Low	1.00 (ref)	1.00 (ref)
Medium	1.21 (0.85, 1.72)	1.00 (0.69, 1.44)
High	1.41 (1.04, 1.90)	1.01 (0.72, 1.42)
Health literacy decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.25 (0.99, 1.58)	1.13 (0.87, 1.47)
Age		
Per year increase	1.04 (1.03, 1.06)	1.06 (1.04, 1.07)
Sex		
Female	1.00 (ref)	1.00 (ref)
Male	0.96 (0.80, 1.16)	0.86 (0.70, 1.06)
Educational attainment		
No qualifications	1.00 (ref)	1.00 (ref)
Up to degree level	1.56 (1.26, 1.92)	1.33 (1.04, 1.69)
Degree level	2.06 (1.58, 2.69)	1.58 (1.17, 2.13)
Net non-pension wealth		
Per increasing quintile	1.50 (1.39, 1.61)	1.33 (1.22, 1.44)
Marital status		
Single	1.00 (ref)	1.00 (ref)
Married or living as married	1.76 (1.44, 2.15)	1.53 (1.22, 1.92)
Self-rated general health		
Fair/Poor	1.00 (ref)	1.00 (ref)
Excellent/Good/Very good	2.00 (1.62, 2.48)	1.57 (1.25, 1.97)
Baseline memory		
Per point increase	1.02 (0.99, 1.05)	0.99 (0.95, 1.03)
Baseline verbal fluency		
Per point increase	1.06 (1.01, 1.11)	1.03 (0.97, 1.09)
Memory decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.13 (0.93, 1.38)	1.13 (0.90, 1.43)
Verbal fluency decline		
Yes	1.00 (ref)	1.00 (ref)
No	1.07 (0.88, 1.29)	1.14 (0.92, 1.41)

The sensitivity analysis separating non-smokers into ‘former’ and ‘never’ smokers showed no difference from the main analysis (the adjusted OR for ‘never’ smoking was 0.95; 95% CI: 0.66–1.39 and for ‘former’ smoking was 0.94; 95% CI: 0.71–1.23 among those with high vs. low baseline health literacy; the adjusted OR for ‘never’ smoking was 0.84; 95% CI: 0.64–1.11 and for ‘former’ smoking was 0.92; 95% CI: 0.76–1.12 for no vs. yes for health literacy decline). The sensitivity analysis separating out from the non-problematic drinkers those who abstained from alcohol at any time point out is shown below in Table 11.10. Overall, 645/3277 (20%) participants abstained at any time point. The model in Table 11.10 is population weighted, and the reference category is ‘problematic’ drinking at any time point (the same as in the main analysis). Adults who did not decline in health literacy were less likely to abstain from alcohol (OR=0.74; 95% CI: 0.55–1.00), and those who had better cognitive function scores at baseline and experienced no cognitive decline were also less likely to abstain from alcohol at any time point (Table 11.10).

Table 11.10 Sensitivity analysis predicting abstaining from alcohol at any time point, waves 2 to 6, n=3277

Predictors	Abstaining at any point Fully adjusted OR (95% CI)
Baseline health literacy	
Low	1.00 (ref)
Medium	1.07 (0.67, 1.71)
High	0.85 (0.55, 1.30)
Health literacy decline	
Yes	1.00 (ref)
No	0.74 (0.55, 1.00)
Age	
Per year increase	1.02 (1.01, 1.04)
Sex	
Female	1.00 (ref)
Male	0.37 (0.29, 0.47)
Ethnicity	
Non-white	1.00 (ref)
White	0.09 (0.03, 0.29)
Educational attainment	
No qualifications	1.00 (ref)
Up to degree level	0.57 (0.42, 0.71)
Degree level	0.51 (0.37, 0.71)
Net non-pension wealth	
Per increasing quintile	0.68 (0.62, 0.74)
Self-rated general health	
Fair/poor	1.00 (ref)
Excellent/good/very good	0.61 (0.45, 0.82)
Baseline memory	
Per point increase	0.93 (0.89, 0.97)
Baseline verbal fluency	
Per point increase	0.93 (0.87, 0.99)
Memory decline	
Yes	1.00 (ref)
No	0.75 (0.58, 0.97)
Verbal fluency decline	
Yes	1.00 (ref)
No	0.87 (0.68, 1.11)

11.4 Discussion

In this longitudinal analysis of ELSA participants initially aged 52-79 years, having high baseline health literacy and not declining in health literacy were positively associated with maintaining weekly MVPA over an eight-year follow-up period from 2004/05 to 2012/13 in comprehensively adjusted, population-weighted models. Adults who scored 4/4 items correct on the health literacy assessment in wave 2 (2004/5) had 39% higher odds of consistently reporting weekly MVPA over the follow-up than those who scored ≤2/4 items correct. Similarly, adults who did not decline in their health literacy score over the follow-up had 34% higher odds of consistently reporting weekly MVPA than those who declined by ≥1 point. Having higher baseline cognitive function and no cognitive decline also positively predicted consistent long-term weekly MVPA, indicating that health literacy and cognitive function may have unique contributing roles in supporting MVPA over time. The other positive predictors of long-term weekly MVPA were indicators of social advantage, including male sex, higher education, greater wealth, and better health. The issue of consistently maintaining regular MVPA during ageing therefore appears to be an issue of health equity among older adults.

In contrast, health literacy and health literacy decline were not independently associated with five-daily fruit and vegetable intake, non-problematic drinking, and non-smoking after adjusting for covariates, indicating that engagement in these behaviours is mainly explained by sociodemographic and health-related factors. Again, indicators of social advantage, including being more highly educated, wealthier, and healthier predicted consistent reporting of five-daily fruit and vegetable intake and non-smoking, while men and those in paid work were less likely to consistently eat five daily fruit and vegetable servings. Non-problematic drinking (i.e. drinking less than almost every day) and abstinence from alcohol were less common among men, adults who were from a white ethnic background, and those who were more highly educated, wealthier, and healthier, indicating that drinking almost every day is a socially patterned behaviour. Cognitive function and cognitive decline were inconsistently associated with these three health behaviour variables.

My results are consistent with two American studies and a Dutch study showing that health literacy is weakly associated with physical activity in older adults (J. S. Bennett et al., 2012; Geboers et al., 2014; Osborn et al., 2011). The Dutch study also found that health literacy was not associated with fruit and vegetable consumption (Geboers et al., 2014). My results are also mostly consistent with another cross-sectional American study of new Medicare enrolees (around age 65), which found that adults with low health literacy, according to the S-TOFHLA, less frequently engaged in regular exercise, more frequently smoked, and more frequently abstained from alcohol than those with adequate health literacy, but that these findings were non-statistically significant after adjusting for sociodemographic factors (Wolf et al., 2007). My results conflict with a cross-sectional UK study of younger adults aged 16-64 years. That study found that health literacy (according to the UK-TOFHLA) was independently associated with fruit and vegetable intake and smoking, but not physical activity (von Wagner et al., 2007). My results may differ from this latter study due to the older age of participants in my study, where physical health or cognitive limitations may have an overriding effect on health behaviours over health literacy. Alternatively, the reduced sensitivity of the health literacy measure used in my study, as compared with the UK-TOFHLA, may have caused adults at the highest levels of functioning to be not differentiated between. Differences in the way physical activity was measured may also explain this discrepancy, where the other study assessed a simple ‘yes’ vs ‘no’ for any physical activity in the past 7 days (von Wagner et al., 2007).

To the best of my knowledge, no other studies have simultaneously examined the roles of health literacy and cognitive function in predicting health behaviour. It appears that health literacy and cognitive function have independent roles in helping to sustain long-term MVPA. The reverse association has been well-characterised for cognitive function, whereby regular physical exercise has been prospectively associated with improved levels of cognitive functions in several epidemiological cohort studies and randomised controlled trials (L. A. Baker et al., 2010; Hillman, Erickson, & Kramer, 2008; Sofi et al., 2011; Weuve et al., 2006). Although I did not show the reverse relationships between physical activity at baseline and each of cognitive function and health literacy in this Chapter, they are shown (to be null in the ELSA) in Appendix 11.1 in the manuscript based on the MVPA analysis presented here, which is under peer review at the *American Journal of Preventive Medicine*.

The potentially causal relationship between cognitive function and engagement in physical activity has been theorised about (Buckley, Cohen, Kramer, McAuley, & Mullen, 2014), but not well investigated. Poor cognitive function has prospectively been associated with poor physical capability, which would in turn reduce one’s likelihood of engaging in physical activity (Clouston et al., 2013). In all likelihood, the relationship between cognitive function and physical activity may act as a feedback loop in older adults. With respect to the analogous relationship for health literacy, it may be that physical activity would help to increase health literacy to the degree that it would help to improve any cognitive functions that contribute to health literacy skills. It could also be that the unmeasured aspects of cognitive function in this study (i.e. reasoning) would have accounted for at least part of the association between health literacy and weekly MVPA. However, health literacy (as assessed by the NVS) has prospectively been shown to be associated with decline in physical functioning in older adults, independently of fluid and crystallised cognitive functions (S. G. Smith et al., 2015a), which could also contribute to the association I observed.

11.5 Limitations

The four health-promoting lifestyle behaviours that I examined in this chapter were assessed at multiple time points by self-report and were subject to recall error (Newell, Girgis, Sanson-Fisher, & Savolainen, 1999; Prince et al., 2008). If recall error in reporting health behaviours is non-differential by health literacy or health literacy decline, then the odds ratios will underestimate the true associations as the recall error adds noise to the data. In particular, the slightly differing ways that fruit and vegetable intake was assessed in waves 3 and 4 versus 5 and 6 might have affected reporting, adding noise to the data (Appendix 11.3). If adults who had low health literacy or who declined in health literacy more frequently reported health behaviours erroneously, then the odds ratios will be biased in a direction that depends on the overall direction of errors and the true association. For example, if high health literacy is truly positively associated with MVPA, and if the participants with high health literacy correctly report MVPA whereas those with low health literacy inconsistently report MVPA so that there are varying overestimates and underestimates, then the association may be affected so that it is an overestimate (if the sum of responses from those with low health literacy skews towards an underestimate), an underestimate (if the sum of responses from those with low health literacy skews towards an overestimate), or it may potentially not be affected (if the sum of responses from those with low health literacy is close to a cancelling out of over- and underestimates). To the best of my knowledge, there has not been any validation study examining the accuracy of self-reported health behaviours according to the health literacy level of participants.

Reassuringly, the frequencies of self-reported health behaviours in this sample were similar to those assessed in the population-representative Health Survey for England (HSE), indicating that attrition in the ELSA does not markedly skew the distribution of these health behaviours (Chaudhury & Esliger, 2009; Fat, 2013; Lifestyle Statistics Team, 2015; Roberts, 2013). Alcohol consumption was slightly lower and physical activity slighter higher in this sample than in the HSE, the latter potentially because the ELSA sample is slightly healthier and wealthier than the general population of England (Steptoe et al., 2013a). The physical activity data in ELSA were validated in a sub-sample of 116 study participants using accelerometer data, showing a moderate correlation (Spearman's r=0.21; p=0.02) (Hamer et al., 2014b). The self-report data are an overestimate of actual activity levels; the same phenomenon has occurred in the HSE (Chaudhury & Esliger, 2009). According to accelerometer data from the 2008 HSE, less than 5% of women aged 55-64 and 0% of women aged 65 and over met the WHO global physical activity recommendation of 150 minutes per week of moderate activity, 75 minutes per week of vigorous activity, or an equivalent combination of the two (Chaudhury & Esliger, 2009; World Health Organization, 2010). Because of the way physical activity was measured in the ELSA, I was unable to define weekly MVPA at a level that directly corresponds to this global recommendation. However, the moderate and vigorous physical activity variables in the ELSA that I used have predictive capability for health outcomes including all-cause mortality, demonstrating their clinical and biological relevance (Hamer et al., 2014a; Hamer et al., 2014b).

Overall, 20% (821/4098) of participants did not return the self-completion questionnaire at one or more time points and were subsequently excluded from the analyses of fruit and vegetable intake and alcohol consumption. Low baseline health literacy was independently associated with non-return at any time point (OR=1.51; 95% CI: 1.15–1.98 for low vs. high baseline health literacy).[12] Health literacy decline was borderline significantly associated with non-return of the self-completion questionnaire (OR=1.20; 95% CI: 0.98–1.48).[12] There were some other independent predictors of non-return of the self-completion questionnaire: non-white ethnicity (OR=4.69; 95% CI: 2.72–8.07), being single (OR=1.80; 95% CI: 1.48–2.19), currently being in paid work (OR=1.60; 95% CI: 1.29–2.01), not having access to a

[12] In a multivariable-adjusted population-weighted logistic regression model adjusted for age, sex, ethnicity, education, net non-pension wealth quintile, marital status, working status, access to a car when needed, self-rated health, limiting long-standing illness, IADL limitations, depressive symptoms, baseline cognitive function, cognitive decline, baseline health literacy, and health literacy decline.

car when needed (OR=1.56; 95% CI: 1.21–2.01), having a lower baseline memory score (OR=0.94; 95% CI: 0.91–0.97 per point increase in memory), and declining in memory score over the follow-up (OR=1.21; 95% CI: 1.00–1.47).[12] These predictors of non-return of the self-completion questionnaire are similar to those observed in Chapter 9.

These missing self-completion questionnaire data have some implications for my results. If low health literacy or health literacy decline are truly associated with fruit and vegetable intake and alcohol consumption, the ability of this analysis to observe these associations would be diminished, as a significant proportion of these adults was excluded due to missing self-completion questionnaire data. I am less worried about the other characteristics associated with non-return of the self-completion questionnaire, as they are control variables and not the main predictor or outcome variables of interest. The use of population-representative weights ensured that the sample was still representative of the target population of home-dwelling English adults aged 50 years and over, despite these missing data.

11.6 Strengths

Strengths of this analysis include its longitudinal nature over an eight-year follow-up period. Health literacy measurements with follow-up data are rare in population-based studies. The ELSA is one of the first available data sources that can investigate the behavioural outcomes of low health literacy or health literacy decline. The logistic regression models were adjusted for physical health and cognitive function and decline variables, a major improvement upon previous behavioural studies of health literacy. I addressed differential study response, attrition, and missing data applying longitudinal population-representative weights to all models.

11.7 Conclusion

In this cohort of older English adults who were initially aged 52 to 79 years and followed up for an eight-year period, baseline health literacy and health literacy decline were statistically significant predictors of consistent weekly MVPA over the follow-up, independently of sociodemographic factors, cognitive function and decline, and physical health. In contrast, health literacy did not appear to play an independent role in long-term fruit and vegetable intake, alcohol consumption, and smoking status. Social inequalities in the long-term patterns of these health behaviours, or least the way in which they were reported, were apparent. Consistent associations were observed between health behaviours and education, wealth, and health, where people who were more socially advantaged were more likely to sustain regular MVPA and fruit and vegetable intake, but also near-daily alcohol consumption over the eight-year follow-up. Cognitive function and cognitive decline also appeared to play an independent role in long-term weekly MVPA, but their associations with other health behaviours were less consistent. In all, the maintenance of health-promoting lifestyle behaviours into later life appears to be an issue of health-related capability and is markedly socially graded.

Chapter 12. General Discussion

12.1 Introduction

The health literacy skills of populations are a growing concern of governments and health organisations worldwide. In modern global economies based on technological advancement and information communication, adults with low literacy skills face social exclusion and poor health and well-being. In the past decade, the health literacy research field has expanded with large-scale international projects such as the European Health Literacy Consortium, the Worldwide Universities Network (WUN) Health Literacy Network, and the Optimising Health literacy to Improve Health and Equity (OPHELIA) project. Addressing low population health literacy is now a goal of the WHO and the American Healthy People 2020 government initiative (Office of Disease Prevention and Health Promotion, 2015; World Health Organization, 2013). A great deal of research has gone into the development of health literacy measurement tools and understanding the antecedents and outcomes of low health literacy that are related to the management of illness, mostly among clinical study samples (Berkman et al., 2011; Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012).

Aside from a small body of cross-sectional research linking performance on functional health literacy measures to performance on tests of cognitive function (Federman et al., 2009; Murray et al., 2011; Reeve & Basalik, 2014; Wolf et al., 2012), the relationships between ageing, cognitive function, and health literacy had been largely unexamined. In particular, longitudinal changes to health literacy during ageing, the roles of cognitive function and cognitive decline in any potential ageing-related changes to health literacy, and the health behavioural outcomes of low and declining health literacy in older adults were unknown. This thesis aimed to examine 'fluid' functional health literacy skills over time during ageing to fill this gap in the literature. The sociodemographic, cognitive, and behavioural predictors of ageing-related health literacy decline, along with the health behavioural outcomes of low health literacy and health literacy decline were investigated in a longitudinal cohort of older English adults. This chapter discusses the main findings of this thesis and the contribution they make to the literature. It reflects on the limitations and strengths of this research and areas for future inquiry.

12.2 Summary of findings and contribution to the literature

My thesis was based on seven research questions, which were addressed in five empirical studies. The first study was a systematic review and meta-analysis of existing evidence on the cross-sectional relationship between age and health literacy according to different health literacy tests. Studies two through five then used data from older English adults in the English Longitudinal Study of Ageing. Studies two and three investigated the sociodemographic, cognitive, and behavioural (Internet use and social engagement) predictors of ageing-related health literacy decline. Studies four and five investigated the health behavioural outcomes (colorectal cancer screening uptake, weekly MVPA, five-daily fruit and vegetable intake, non-problematic alcohol consumption, and non-smoking) of low health literacy and ageing-related health literacy decline. This section summarises the findings of these studies according to the seven research questions, and discusses their contributions to this field of research.

12.2.1 What is the association between age and health literacy in older adults, overall and according to different health literacy tests?

According to national surveys of health literacy and smaller studies of health literacy in older adults in various contexts, older age appears to be negatively associated with health literacy (D. W. Baker et al., 2000; Bostock & Steptoe, 2012; Calkins Aguirre et al., 2005; Canadian Council on Learning, 2008; Kutner et al., 2006; Paasche-Orlow et al., 2005; M. Williams et al., 1998; Wolf et al., 2012). I aimed to formally synthesise the existing evidence on the relationship between age and health literacy for two main purposes: 1) to inform the hypotheses for future longitudinal studies on the relationship between age and health literacy, and 2) to further clarify the relationship between cognitive function and health literacy.

My hypothesis about the relationship between age and health literacy was informed by the epidemiological and psychological literatures on cognitive ageing. Previous research has shown that fluid cognitive functions involving reasoning, short-term memory, processing speed, and verbal fluency decline in a non-pathological fashion with age beginning around 45 years or younger, and, that crystallised cognitive functions including vocabulary, numeracy, and long-term stored knowledge show little decline with age (Deary et al., 2009; O'Carroll, 1995; Singh-Manoux et al., 2012). Given that fluid cognitive functions map onto the TOFHLA and NVS assessments and that crystallised cognitive functions map on the REALM assessment (Wolf et al., 2012), I hypothesised that performance on these tests would show similar relationships with age as the cognitive functions they are correlated with.

The systematic review and meta-analysis in Chapter 6 included data on 33,379 study participants from nine different countries, speaking nine different languages. The results showed that, on average, older adults (mostly aged 65 years and over) performed worse on the TOFHLA or S-TOFHLA than younger adults (mostly aged less than 65 years), with the random-effects pooled OR for the relationship between older age and limited health literacy being 4.20 (95% CI: 3.13–5.64). In contrast, performance on the REALM was weakly associated with age, with older adults having a random-effects pooled OR of 1.19 (95% CI: 1.03–1.37) for limited health literacy. Hence, the relationship between age and health literacy appears to depend on the tool used to assess health literacy, highlighting that health literacy is not a singular construct, even when defined as ‘functional’ health literacy. In research, a person’s level of health literacy depends on how health literacy is defined, measured, and scored. The common tests of functional health literacy (i.e. the TOFHLA and the REALM) overlap with tests of cognitive function (Wolf et al., 2012), leading to a conflation between the constructs of health literacy and cognition in older adults.

The results of this systematic review and meta-analysis were consistent with a narrative review of American studies conducted about ten years prior, which found that age was inversely associated with performance on tests of functional health literacy (Paasche-Orlow et al., 2005). Results are also consistent with national surveys of health literacy in North America and general literacy in England and in OECD countries (Canadian Council on Learning, 2008; Harding et al., 2012; Kutner et al., 2006; OECD, 2013a). In a German study using the subjective health literacy measures developed for the HLS-EU-Q (reviewed in Chapter 2), titled the Cardiovascular Disease, Living, and Ageing in Halle (CARLA) study, self-rated health literacy increased with age in adults aged 45 to 83 years with high prevalence of hypertension, diabetes, obesity, and other cardiovascular risk factors (Tiller, Herzog, Kluttig, & Haerting, 2015). In this study, a shortened version of the HLS-EU-Q was used (the HLS-EU-Q-16), and an index score from 0 to 50 for health literacy was used. Self-rated health literacy increased linearly with age, in contrast to my results and other results using objective measures. These findings might be because the HLS-EU-Q-16 measures a person’s self-rated ability to deal with health issues in their day-to-day lives, including finding, appraising, and applying information in day-to-day life (Tiller et al., 2015). These self-rated skills, as opposed to objective measures of active learning using written health materials such as the TOFHLA, may increase with age due to increasing life experience with managing health problems.

Despite this evidence for their opposite associations with age, there does appear to be a consistency between objective and subjective measures of health literacy in terms of their relationships with education, income, and other socioeconomic indicators. Objective and subjective health literacy are consistently higher in adults who are better educated, wealthier, in better jobs, and who are generally more socioeconomically advantaged, indicating some degree of validity across both types of measures (HLS-EU Consortium, 2012; Paasche-Orlow et al., 2005; Tiller et al., 2015). Better understanding of the relationships between objective and subjective measures of health literacy may help to improve future measures of health literacy. People may sometimes be their own best judge of the skills they need in their specific environments to manage their specific health concerns (Bryant, Corbett, & Kutner, 2001). Existing measures do not account for this contextual nature of health literacy. Older adults may in fact be better at relying on learned experiences and long-term health practices to manage their health, even in the face of cognitive ageing and potentially reduced capacity for active learning. In future, a combination of objective and subjective measures may better help pinpoint the nature of the association between age and health literacy, and how lifetime experiences might influence the ability to deal with health issues.

12.2.2 Does health literacy decline during ageing, and, if so, at what age(s) might older adults become vulnerable to decline in health literacy?

When developing the aims of this thesis, I identified an absence of longitudinal data on potential changes to health literacy during ageing in the existing literature. I conducted a scoping literature review, observing that health literacy is often inversely associated with age in the existing cross-sectional research (see Chapter 1). This association can easily lead to the assumption of a causal effect of ageing on health literacy skills. While this explanation is probable, because of cognitive ageing, it could also be that older generations of adults have lower health literacy than younger adults due to a cohort effect. For example, educational experiences may greatly differ between adults in their 80s (born 1922 and earlier in this sample) and adults in their 50s (born as late as 1952 in this sample), due to governmental policy changes over the mid-20th century that led to the expansion of educational opportunities over time (Lawson & Silver, 2007). Given the known cross-sectional association between health literacy and education, it is possible that age differences in health literacy skills can be partly explained by early-life educational factors. Whether better quality of education contributes to better cognitive reserve or cognitive function, which I hypothesised to protect against ageing-related health literacy decline, is not known. If this relationship were true, it could also explain any cohort effect observed in health literacy skills.

Using longitudinal data with a six-year follow-up from the English Longitudinal Study of Ageing, Chapter 8 of this thesis aimed to identify whether health literacy declines during ageing, and, if so, at what age older adults might become vulnerable to decline in health literacy skills. The analysis presented in Chapter 8 identified that about one-fifth of English adults aged 52 years and over decline in health literacy over a six-year follow-up period, defined as declining by one or more points on a four-item functional health literacy measure. Health literacy decline appeared to usually begin around age 65 years, with adults aged less than 65 years showing no decline in health literacy skills, on average. After age 65 years, health literacy declined, on average, with the magnitude of decline increasing with age. Adults aged 80 years and over had over three times greater odds of experiencing health literacy decline over the six-year follow-up than those in their early 50s. This finding supports my hypothesis that health literacy tends to be lower in older adults because it tends to decline with age, rather than a pure cohort effect of older adults having lower health literacy than younger adults to begin with for whatever reason. This longitudinal finding was consistent with the results of the systematic review and meta-analysis presented in Chapter 6, as well as other cross-sectional research showing an inverse association between age and health literacy (Paasche-Orlow et al., 2005). Overall, my results for this question indicate that, on average, health literacy declines during ageing, beginning around age 65 years, in about one-fifth of the older population of England.

12.2.3 What are the sociodemographic risk factors for ageing-related health literacy decline?

Because there had been no longitudinal data on health literacy decline during ageing prior to the ELSA, the sociodemographic risk factors for ageing-related health literacy decline had been unknown. I asked this research question in order to identify which population subgroups may be the most vulnerable to loss of health literacy skills during ageing. I see low health literacy and health literacy decline as issues of health equity, whereby people have differential opportunities to gain and maintain health literacy and cognitive skills throughout their lives. Experiences in early-life, in the education system, in work, and in leisure-time may affect health literacy skills. Just as health literacy skills are socially patterned according to various socioeconomic factors and sometimes gender and ethnicity in cross-sectional analyses, as reviewed in Chapter 2, I hypothesised that the population distribution of ageing-related health literacy decline was also likely to be socially patterned.

The second objective of the study in Chapter 8 was therefore to examine the sociodemographic risk factors for ageing-related health literacy decline. This study identified that health literacy decline among older adults is marked by social inequalities, whereby men and all adults from deprived social backgrounds were the most vulnerable to skill loss during ageing. Cognitive function and even slight cognitive decline appeared to affect the likelihood of health literacy decline. After accounting for measures of cognitive function and decline in the main model, the associations between each of gender, ethnicity, and health literacy decline were attenuated to borderline statistical significance, partly because women and white adults tended to have slightly higher cognitive function scores than men and non-white adults, respectively. The magnitude of association between gender and health literacy decline was small. The association between ethnicity and health literacy decline had a wide confidence interval due to the small proportion of minorities in the sample, which may also have contributed to the non-significance of these findings. Importantly, the associations between educational attainment, occupational class, and health literacy decline were independent of cognitive function and decline. These findings indicate that there is a direct effect of these factors on health literacy decline that is independent of the cognitive measures used in this analysis.

These results are consistent with previous cross-sectional evidence indicating that health literacy is lower among adults with low education (Bostock & Steptoe, 2012; Calkins Aguirre et al., 2005; Canadian Council on Learning, 2008; Kutner et al., 2006; Rowlands et al., 2013; von Wagner et al., 2007). Previous research has been inconsistent as to whether health literacy is differential by gender or ethnic group; these relationships are likely to depend on the social contexts in which men and women and people from different ethnic backgrounds would have the opportunities to gain and maintain health literacy skills throughout their lives. Thus, study samples from different places with differing age distributions might show divergent results for the associations between gender, ethnicity, and health literacy skills. This study was slightly statistically underpowered to assess the relationship between ethnicity and health literacy decline, as a very small proportion of the English population over age 50 is not white. The 2011 *Skills for Life Survey* showed that lower general literacy scores in non-white adults versus ‘White British’, ‘White Irish’, or ‘White Other’ adults living in England are mostly due to English language proficiency problems, rather than literacy problems (Harding et al., 2012).

Overall, consistent with previous literature on the cross-sectional determinants of health literacy test performance, ageing-related decline in health literacy skills appeared to be socially patterned. The sociodemographic predictors of health literacy decline were mostly independent of cognitive function and decline measures, indicating a direct effect of social position on literacy. Opportunities to maintain the literacy skills required for personal health management do not appear to be equally distributed in the older population in England, making health literacy an issue of health equity during ageing.

12.2.4 What are the roles of cognitive function and cognitive decline in ageing-related health literacy decline?

The systematic review and meta-analysis in Chapter 6 found limited evidence for the role of cognitive function in the relationship between age and health literacy. Only five of the 60 cross-sectional studies included in the review examined the potential mediating role of cognitive function in the relationship between age and health literacy. In these studies, evidence was conflicting as to whether adjustment for measures of cognitive functioning or cognitive impairment accounted for any relationship between age and health literacy. Measures of cognitive impairment, such as the MMSE, did not appear to explain any of the inverse association between age and health literacy. There were two studies that assessed the mediating roles of fluid cognitive and sensory functions in the relationship between age and health literacy, and they showed conflicting results (Levinthal et al., 2008; Morrow et al., 2006). From the review, I concluded that further longitudinal evidence was needed to determine the extent to which cognitive decline during ageing may explain ageing-related health literacy decline.

In Chapter 8, I examined the explanatory roles of cognitive function and decline, namely in memory (immediate and delayed recall) and verbal fluency, in the association between age and health literacy decline over a six-year follow-up period. To the best of my knowledge, this study was the first to track health literacy skills over time in an ageing sample. I found that even subtle, one-point increases in baseline memory score (out of 24 points) and baseline verbal fluency score (out of nine points) were associated with reduced odds of experiencing health literacy decline. Similarly, declines of any magnitude on the memory or verbal fluency assessments over the follow-up strongly predicted decline on the health literacy assessment. Together, cognitive function and decline appeared to account for most of the increased odds of health literacy decline with increasing age. However, there was a residual association between age and health literacy decline in the 80 years and over age group that was not explained by these measures of cognitive function. It might be that aspects of cognitive function that were unmeasured in the ELSA, such as reasoning, would have explained this residual relationship.

My finding that cognitive function and decline mostly explained the relationship between older age and health literacy decline was expected based on previous cross-sectional evidence showing that the constructs of cognition and health literacy overlap to a large degree (Kaphingst et al., 2014; Kobayashi et al., 2015; Levinthal et al., 2008; Mõttus et al., 2014; Wolf et al., 2012). Recent cross-sectional research that I conducted using the LitCog cohort of adults aged 55 to 74 years in Chicago, USA indicates that individual cognitive functions have differential relationships with fluid health literacy skills, as assessed by the TOFHLA and the NVS (Kobayashi et al., 2015). I found that while each of processing speed, short-term memory, inductive reasoning, prospective memory, and long-term memory mediated the inverse relationship between age and TOFHLA score to some degree, processing speed was by far the strongest mediator and prospective and long-term memory minimally contributed to the mediation (Kobayashi et al., 2015). On the other hand, no one single cognitive function mediated the inverse relationship between age and NVS score, but the incremental contributions of individual cognitive functions led to an overall mediating effect of fluid cognitive function on the age-NVS score relationship (Kobayashi et al., 2015). Unfortunately, the measure of mental processing speed in the ELSA was not independent of literacy skills, as it required the participant to quickly search for and cross off target letters in a grid of alphabet letters. However, *post-hoc* adjustment for mental processing speed in my studies did not change my results in this thesis.

Contrary to my results presented in Chapter 8, the association between age and health literacy was independent of cognitive impairment according to the MMSE score in previous research (Armistead-Jehle et al., 2010; D. W. Baker et al., 2002;

Gazmararian et al., 1999), although the MMSE does not detect subtle individual differences in cognitive function. An important aspect of my study results is that not everyone who experienced cognitive decline also experienced health literacy decline. About one-fifth of adults actually improved in their health literacy score over the six-year follow-up. However, improvement in score was non-differential by age. Improvement in health literacy score may have been due to learning from repeated exposure to the assessment in waves 2 and 5 of the ELSA, practice and learning of literacy and cognitive skills over the six-year period that elapsed between the two assessments, or due to participant error or guessing in response to the assessment at either time point. It is difficult to speculate about the degrees to which these three scenarios may have occurred. However, I assume that there must be random error in the responses that would account for a small degree of both improvement and decline on the health literacy measure. The fact that the frequency of decline increased with age, while improvement was non-differential by age, indicates to me that decline is an ageing-related phenomenon and not due to random response error.

The degree to which typical cognitive ageing versus ageing-related cognitive impairments of varying severities affects health literacy remains to be elucidated. Whether there is a threshold of cognitive ageing in specific functions beyond which functional literacy skills are affected is unknown. My study suggests that cognitive function is associated with health literacy in an incrementally graded fashion in older adults, and that non-pathological cognitive decline of any magnitude during ageing negatively affects health literacy skills. Further longitudinal studies that address the fluidity of various literacy and cognitive skills during ageing, ideally with measurements taken at multiple time points and with more sensitive measures than mine, are needed for consideration alongside my studies.

My research indicates that the fluid cognitive functions of memory and verbal fluency certainly play a substantial role in predicting health literacy decline over time; they explain the inverse association between age and health literacy, and most of the relationships between health literacy and health behavioural outcomes. However, does this overlap mean that research on health literacy is redundant? Some cognitive epidemiologists argue that health literacy is a redundant construct against cognitive ability (Gale et al., 2015; Mõttus et al., 2014; Reeve & Basalik, 2014). I argue that although current measurement tools used to assess health literacy (e.g. the TOFHLA, the REALM, the NVS, and the IALLS measure used in this thesis) conflate literacy and cognitive function, the concept of health literacy is not redundant and it is an important topic in public health.

Literacy and language skills are learned from a remarkably early age, even earlier than ‘intelligence’ or cognitive ability may be tested (Dickinson & Tabors, 2001; Snow, 1983). The degree to which infants and children are spoken to and with by parents and caregivers, and their exposure to written material at home influences their verbal skills, indicating a clear non-heritable component to these skills. This relationship is summarised eloquently in the National Literacy Trust’s *State of the Nation* report (National Literacy Trust, 2014):

> *For all children, the quality of the home learning environment is more important for intellectual and social development than parental occupation, education or income. In other words, what parents do to stimulate their young children’s development is more important than who they are. Providing an environment that promotes a love of reading matters; the more children’s books, either owned or borrowed, there are in the home, the better a child’s reading and language skills.*

Although whole life-course evidence on health literacy is not available at this point in time, it seems reasonable that literacy and language skills learned beginning in early life would be related to literacy and language skills in later life. Ongoing birth cohort studies, such as the Millennium Cohort Study, may be valuable resources that can measure early life learning and home environment factors in relation to literacy, language, and cognition at multiple time points later on across the life course (Connelly & Platt, 2014).

12.2.5 Could Internet use and social engagement (known protective factors against cognitive decline) protect against health literacy decline during ageing?

I asked this question because I was interested to see whether any behavioural practices could help older adults to maintain health literacy skills during ageing, and, if so, whether this was independent of cognitive function and decline or not. I selected Internet use and social engagement in intellectually stimulating activities, as both types of activities have been shown to protect against cognitive decline during ageing in large, longitudinal cohort studies (Bassuk et al., 1999; Giles et al., 2012; Kraft, 2012; Mitchell et al., 2012; Thomas, 2011b; Wang et al., 2013). Internet use, involving the use of practical applications and with outcomes of accessing and learning from new information, has been shown in several randomised controlled trials to improve performance on measures of cognitive functioning over various types of non-stimulating control conditions in older adults (Chan et al., 2014; Jak, Seelye, & Jurick, 2013). The evidence for social activities from randomised trials is more conflicting; it appears that mentally engaging activities that actively train novel skills may help to improve cognitive functions, while participation in passive social activities may not (Park et al., 2014). I hypothesised that the relationships between Internet use, intellectually stimulating social activities, and cognitive ageing might extend to health literacy skills, either acting through cognitive function or through directly improving literacy.

In this study, presented in Chapter 9, I found that the penetrance of Internet use increased over time from 2004 to 2010 across all adults, but more so in adults who did not decline in health literacy over that time period. In contrast, people's reported engagement in social activities (which were civic activities, leisure activities, and cultural activities) generally remained constant at all points in time. However, engagement in all social activities was consistently higher among adults who did not decline in health literacy than among those who did decline. After accounting for sociodemographic, health-related, and cognitive variables, those who consistently used the Internet across the follow-up were less likely to decline in health literacy than those who sporadically used or did not use the Internet (OR=0.77; 95% CI: 0.59–0.99). Consistent engagement in civic or leisure activities was not associated with health literacy decline, but those who engaged in cultural activities at least once per year were less likely to decline in health literacy than those who engaged in cultural activities less than once per year (OR=0.70; 95% CI: 0.54–0.91). The four types of activities (Internet use, civic activities, leisure activities, and cultural activities) together demonstrated an additive protective effect on health literacy decline, where the more activities engaged in, the greater the magnitude of association.

The results of this study are consistent with recent literature. Around the same time as this study was conducted, other research using the ELSA data showed that Internet use is protectively associated with delayed recall during ageing (Xavier et al., 2014). Cross-sectionally, Internet use has been shown to be more frequent among adults with adequate health literacy than in those with low health literacy (Echt & Burridge, 2011; Wister et al., 2010). Performance on functional health literacy assessments was also shown to improve among adults diverse by age and culture in a systematic review of randomised, theory-based, online 'eHealth' interventions to improve health literacy that were mostly focused on the learning of new health information (R. J. Jacobs et al., 2014). Taken together with this literature, my results indicate that Internet use helps to promote health literacy both indirectly through improving cognitive functions and directly through training literacy skills.

The social activities that I examined in Chapter 9 have never been examined as predictors of health literacy, either cross-sectionally or longitudinally as I have done so here. My hypothesis that consistent engagement in mentally stimulating civic, leisure, and cultural activities would be protectively associated with health literacy during ageing was partly supported. In retrospect, it is not surprising that engagement in leisure activities displayed no association with the maintenance of health literacy over time. The measure of leisure activities in the ELSA assessed membership in social clubs, sports clubs, gyms or exercise classes, or other types of organisation, clubs, or societies. This measure was incredibly vague. There is no indication of the specific types of clubs within each of these categories, and no indication of the actual activities engaged in as part of these clubs and the frequencies they were engaged in. Thus, this measure likely captured passive participation in social activities that do not involve the learning of new skills (not associated with cognitive improvement), in addition to truly stimulating and novel activities in social environments (positively associated with cognitive improvement) (Park et al., 2014). Thus, the measure of leisure activities that I had was probably not specific enough to validly assess whether any leisure-time social activities may contribute to the maintenance of health literacy skills during ageing.

I was somewhat surprised that engagement in cultural activities, but not civic activities was protectively associated with health literacy decline, independently of sociodemographic, health-related, and cognitive factors. The civic activities included being a member of a political party, a trade union, an environmental group, a church or religious group, and volunteering. The cultural activities included attending a cinema, art gallery, museum, theatre, concert, or opera performance in the past year. Again, these measures were vague, as they did not specify the person’s particular role and activities within the aforementioned civic organisations, or the types of cultural activities attended and the level of engagement with them. Civic activities could directly use literacy, cognitive, and communicative skills, depending on the person’s role within the organisation. Cultural activities could use several fluid cognitive and literacy skills, depending on the specific show or exhibit. Despite the imprecision of the measures I had, my results in this area were consistent with longitudinal evidence showing that mentally stimulating social and cultural activities are protectively associated with performance on measures of cognitive function over time (Fratiglioni, Paillard-Borg, & Winblad, 2004; Mitchell et al., 2012; Vemuri et al., 2014; Wang et al., 2013).

In all, this study was a valuable early longitudinal investigation in this area. It should bring about several new hypotheses about social and cognitive processes that influence the dynamics of literacy changes at older ages, and how they may be modified. This study brings to attention the usefulness of understanding health literacy in later life in the context of the social environment, rather than purely in terms of cognitive functions.

12.2.6 Are health literacy and ageing-related health literacy decline related to participation in colorectal cancer screening through the organised national cancer screening programme in England?

In this study, I questioned whether low health literacy and health literacy decline might negatively predict participation in FOBt screening for colorectal cancer in England's national screening programme (the NHS BCSP). The rationale for this study was that the BCSP communicates with the public solely through written information sent to people's homes through the post, without direct contact with a health care professional. Screening-eligible adults (men and women aged 60 to 74 years for FOBt screening) receive a letter of invitation and an informational booklet intended to support informed decision-making ('*Bowel Cancer Screening: The Facts*'). Two weeks later, the FOBt kit and instructions on how to complete it and send it back arrive.

I hypothesised that low health literacy might be a direct barrier to reading, understanding, and using '*The Facts*' leaflet to make a decision about screening, and therefore might be related to non-uptake of screening. Health literacy decline would be a barrier to screening in a similar way. In a statistical model predicting uptake of FOBt screening in screening-eligible adults with high vs. low health literacy adjusted for sociodemographic factors, I found that adults with high health literacy had nearly 30% higher odds of participating in FOBt screening than those with low health literacy (OR=1.28; 95% CI: 1.01–1.64). However, this relatively small effect was entirely explained by measures of memory and verbal fluency; it was attenuated to the null after these cognitive measures were added to the model, with the final OR=0.98 (95% CI: 0.73–1.32). I had originally published this work without adjustment for cognitive function measures, but included them after Gale et al.

published on the same association with the hypothesis that cognitive ability might explain the association I had observed between health literacy and screening uptake.

I suspect that Gale et al. found that cognitive function explained the association between health literacy and cancer screening partly because of how these constructs are measured in the ELSA. In the ELSA, there is overlap between the measures of cognitive function and health literacy. In particular, the measure of mental processing speed is assessed using a test of written alphabetical letter cancellation, and is not independent of literacy. Inherent to Gale et al.'s study is their assumption that 'cognitive ability' precedes and determines literacy skills, while my assumption is that cognitive and literacy skills are developed in tandem throughout the life course. My stance is that it is dangerous to reduce health literacy to 'domain-specific, contextualised measures of basic cognitive abilities' (Gale et al., 2015), as this perspective leaves no room for learning or practice of literacy skills in helping to develop functional abilities. Although there are methodological and conceptual issues regarding the measurement of 'health literacy', it seems too early to deem it a redundant concept against that of 'cognitive ability'.

In addition to Gale et al.'s study, my results for this analysis were consistent with research associating health literacy with FOBt screening knowledge, attitudes, and uptake (Arnold et al., 2012; Dolan et al., 2004; Miller et al., 2007; N. S. Morris et al., 2013; Peterson et al., 2007). However, my results were inconsistent with two studies showing no association between REALM-assessed health literacy and FOBt screening uptake, which may be because the REALM does not comprehensively measure the reading comprehension, reasoning, and judgement skills that are used to make a decision about cancer screening (Miller et al., 2007; Peterson et al., 2007). Consistent with mine and Gale et al.'s findings, measures of fluid cognitive functions have been shown to explain the relationship between health literacy and retention of information about colorectal cancer screening (E. A. H. Wilson et al., 2010).

Relative to sociodemographic factors, health literacy and cognitive function were minor predictors of FOBt screening uptake in my study. Younger adults within the screening-eligible age range, women, those with higher educational attainment, with higher net non-pension wealth, and who were married were more likely to take up FOBt screening, consistent with other research findings (Lo et al., 2015; Logan et al., 2012; van Jaarsveld, Miles, Edwards, & Wardle, 2006; von Wagner et al., 2011). However, literacy and cognitive function are more feasible intervention targets for the improvement of uptake and public engagement with decision-making, as sociodemographic factors are, for the most part, unmodifiable within the power of the screening programme administration. Health literacy has recently been shown to mediate about 9% of the overall socioeconomic inequality in FOBt screening uptake in England, indicating that adapting the screening programme communication methods to better account for low health literacy in the population would improve overall uptake and narrow the socioeconomic gap in uptake of the programme (Solmi et al., 2015).

Overall, my study showed that health literacy has a small association with FOBt screening uptake in England, which is mostly explained by measures of cognitive functioning taken around the same time as the screening test. There are deep social inequalities in screening uptake, which may be addressed through altering the literacy and cognitive burdens of the screening invitation. Other studies have shown that adults with low health literacy experience a greater burden of information processing when reading the informational leaflet that is provided in the BCSP, and also do not retain learned information about colorectal cancer screening as well as those with adequate health literacy (von Wagner, Semmler, et al., 2009; E. A. H. Wilson et al., 2010). Simplified written 'gist' information has also been shown to not be an effective communication method for FOBt screening in England (S. G. Smith et al., 2015b). Communication methods that are alternative to written information for the screening invitation may be the most effective in increasing uptake and reducing social inequalities. Literacy and cognitive barriers to screening should be simultaneously reduced, as these issues appear to go hand in hand.

12.2.7 Are health literacy and ageing-related health literacy decline associated with long-term engagement in health-promoting behaviours (weekly moderate-to-vigorous physical activity, five-daily fruit and vegetable intake, non-problematic drinking, and non-smoking) during ageing?

In this study, I aimed to investigate the roles of health literacy and ageing-related health literacy decline in the long-term consistent maintenance of health-promoting lifestyle behaviours over an eight-year period. The behaviours that I considered were weekly moderate-to-vigorous physical activity (MVPA), five-daily fruit and vegetable servings, non-problematic drinking, and non-smoking. This study was informed by theoretical models of health literacy and health outcomes and health actions (Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009a). I identified that little previous research had focused on the relationship between health literacy and behaviours related to the management of health, as opposed to the management of illness, and particularly not in a longitudinal fashion while accounting for health-related and cognitive covariates. Hence, this study was intended to fill a gap in the literature on the health behavioural outcomes of low and declining health literacy.

Overall, 55% of ELSA participants aged 52-79 years consistently reported MVPA at least once weekly from waves 2 through 6 (eight-year follow-up), 23% consistently reported consuming five daily fruit and vegetable servings, 72% consistently reported non-problematic drinking, and 87% consistently reported not smoking. All of these health-promoting behaviours, with the exception of fruit and vegetable intake, were graded by health literacy at baseline; the strongest being weekly MVPA, which was consistently engaged in by 35% of adults with low health literacy and 60% of adults with high health literacy. Interestingly, non-problematic drinking was more common among adults with low than with high health literacy (77% vs. 71%). Those who drank 'problematically' (defined as drinking 'almost every day'), were more likely to be male, white, well-educated, and wealthier, indicating that regular drinking is a socially patterned behaviour. The participants in the ELSA cohort may also not be representative of the whole spectrum of alcohol use: because the ELSA sample tends to be healthier than the general population aged 50 and over (Marmot et al., 2003), it might be that the heaviest users of alcohol were not captured in my analysis.

Following adjustment for sociodemographic, health-related, and cognitive covariates, only the long-term maintenance of MVPA was independently associated with baseline health literacy (OR=1.39; 95% CI: 1.04–1.84 for high vs. low). Maintaining health literacy over the follow-up was also independently positively associated with maintaining weekly MVPA over the follow-up (OR=1.34; 95% CI: 1.10–1.63). Having higher baseline cognitive function and no cognitive decline were also positively predictive of consistent long-term weekly MVPA.

My results indicate that health literacy and cognitive function have unique, yet overlapping roles in supporting the maintenance of MVPA over time. This finding is consistent with longitudinal evidence from a cohort of older adults in Chicago, USA demonstrating that low health literacy at baseline (assessed by the NVS) is associated with declines in physical functioning over a three year follow-up period (S. G. Smith et al., 2015a). Although health literacy was assessed before the longitudinal health behaviour variables in this analysis, there might be a further prior 'upstream' factor that causes good physical and cognitive function during ageing; if this were the case, then high health literacy, good cognitive function, and good physical function would simply be correlates of some kind of 'healthy ageing' factor.

I have considered this possibility, informed by the 'system integrity' hypothesis for the association between childhood cognitive ability and late-life mortality coming out of the cognitive epidemiology literature (Whalley & Deary, 2001). In this hypothesis, childhood cognitive ability is seen as a general and moderately stable indicator of bodily system integrity, which is indexed as the 'efficiency of information processing in the nervous system' (Whalley & Deary, 2001). The ELSA dataset is not equipped to assess this hypothesis; the early-life determinants of literacy, cognition, and physical function and how they develop in tandem through to later-life are not well understood. Other research using data that spans as much of the life course as possible will have to investigate the possibility of inherent 'system integrity' accounting for both health literacy and physical function in later life. Again, birth cohort studies such as the Millennium Birth Cohort may provide the required data for this kind of analysis.

I found that the strongest predictors of consistent weekly MVPA were indicators of social advantage: being male, wealthier, more highly educated, and healthier. The resources conferred by these aspects of social position might help to support consistent engagement in physical activity. For example, social norms surrounding gender, the financial resources to access facilities, classes, and equipment for exercise, the knowledge and access to information conferred by education, and the physical capability conferred by good physical health would all act to help support engagement in physical activity (M. A. Adams et al., 2015; Koeneman et al., 2011). In this way, health literacy can be seen as another type of 'resource' used by well-educated and socially advantaged adults to help support the maintenance of physical activity during ageing.

This hypothesis is based on Link and Phelan's 'fundamental cause' theory (Link & Phelan, 1995). Briefly, 'fundamental cause' theory posits that social conditions may be fundamental causes of ill health, as they involve access to resources that help people avoid ill health through a variety of mechanisms (Link & Phelan, 1995). A core aspect of the theory is that even if an intervening mechanism between a fundamental social cause and a health outcome is modified or removed, an association between the social cause and the outcome will re-emerge (Link & Phelan, 1995). For example, if education is a fundamental social cause of MVPA (which, technically, is a behaviour and not a health outcome, but the same principle applies), then altering any mediators on the pathway between education and MVPA (such as, potentially, health literacy) will still not eradicate this main overarching relationship. Given that socioeconomic inequalities in MVPA have been consistently observed in adult populations in several developed countries, it is possible that socioeconomic conditions are a ‘fundamental cause’ of physical activity behaviour (Demarest et al., 2014; Droomers, Schrijvers, & Mackenbach, 2001; Farrell, Hollingsworth, Propper, & Shields, 2014; Harper & Lynch, 2007; P. Smith, Frank, & Mustard, 2009; Stamatakis et al., 2014). The potential mediating role of health literacy in the relationship between socioeconomic conditions and MVPA in later life is an interesting area for future research.

Overall, this study indicated that the long-term engagement in health-promoting lifestyle behaviours, or at least the way in which they were reported, is socially patterned. I observed consistent associations between health behaviours and education, wealth, and health. Health literacy and health literacy decline, along with cognitive function and decline, appeared to play independent roles in long-term weekly MVPA, but not in the other three health behaviours. In all, the maintenance of health-promoting lifestyle behaviours into later life appears to be an issue of health-related capability and is markedly socially graded.

12.3 Overview and implications

Low and declining health literacy are prevalent among English adults aged 52 years and over, with about one in three being unable to correctly answer four basic reading comprehension questions about a medicine label, and about one in five declining in their score over a six-year period. Health literacy decline appears to begin, on average, around age 65 years, and becomes increasingly frequent with increasing age. It is closely linked with poor cognitive function and cognitive decline. There are marked social inequalities in health literacy decline, whereby men and all adults from deprived social backgrounds are the most vulnerable to losing health literacy skills during ageing. However, health literacy decline is not inevitable, and consistent engagement in intellectually stimulating social and technological activities might contribute to the maintenance of health literacy skills, independently of cognitive function and decline. Health literacy appears to play a minor role in promoting health behaviours such as colorectal cancer screening and moderate-to-vigorous physical activity; it likely acts in tandem with good cognitive and physical functioning to support engagement in health-promoting behaviours. Overall, health literacy may represent one of several resources that socially advantaged adults utilise to maintain good health as they age.

A theme that has run through this thesis is the relationship between health literacy and cognitive function. The intersection between literacy and cognition is difficult to navigate, conceptually and politically. This issue arises due to the way health literacy is measured in most objective assessments, including the TOFHLA, REALM, NVS, and the IALLS measure that was used in this thesis. These assessments operationalize functional health literacy skills as reading comprehension, reasoning, and vocabulary in medical or health-related contexts. Consequently, there is inherent overlap between health literacy and cognitive functions due to how they are measured. Differential psychologists have identified this overlap, and used it to argue that health literacy is a concept of scientific redundancy and, rather, that measures of cognitive ability or intelligence should be used in research (Reeve & Basalik, 2014). In practical terms, literacy skills are never used in isolation from cognitive skills in everyday life, and vice versa, so the separation of the two seems an almost purely academic exercise. However, it is important to delineate literacy skills and cognitive abilities, even if only for the reason that the intelligence research field posits that intelligence is a genetically determined and unitary trait that is stable throughout life (Calvin et al., 2011; Hernstein & Murray, 1994).

If the above is true and if health literacy is no more than a marker of intelligence, then public health efforts to increase health literacy in order to reduce health inequalities between social groups would be fruitless. This question is especially relevant in today's socially and economically unequal world. We have recently seen the development of 'cognitive epidemiology', a subfield of epidemiology whose goal is to 'use cognitive ability test scores as risk factors for human health and disease outcomes, including mortality' (Deary & Batty, 2007). Given the field's central dogma of intelligence as a heritable and unitary trait, the purpose of cognitive epidemiology is to show a predetermined genetic basis for a range of health outcomes. Indeed, cognitive epidemiologists postulate that measures of intelligence will be the underlying cause of social class and racial/ethnic inequalities in health (Batty, Der, Macintyre, & Deary, 2006).

Following the results of this thesis, I do not support the conceptualisation of intelligence as a fixed, entirely heritable, and unitary ‘trait’, against which health literacy is redundant. As *g*, intelligence consistently has low explanatory power to describe the shared variance of multiple cognitive tests, and health literacy consistently explains health behaviours and outcomes over and above measures of cognitive function in my research and in others (Bostock & Steptoe, 2012; S. G. Smith et al., 2015a; Wolf et al., 2012). Rather, I support the notion of several cognitive functions that are inter-linked, and, while heritable to a degree, highly malleable by environmental exposures including educational and experiential learning across the life course (Singh-Manoux, 2010). At the same time, I propose that with respect to predicting health behaviours and outcomes, it is not necessarily useful to separate cognitive function and literacy during ageing as they are so closely linked in everyday, practical terms. I write this with the caveat that low literacy should be directly addressed among those people who are at the bottom of the spectrum of literacy skills and have real functional problems with reading comprehension, as opposed to problems with processing, reasoning with, and using health information to make decisions (i.e. how low health literacy is usually conceptualised).

Returning to the words of Scott Simonds in 1974, which sparked the entire health literacy research field, early-life education is probably the most feasible point of intervention to raise the health literacy of the population (Simonds, 1974). This ambition would not be effective if health literacy is assumed to be a domain-specific application of a genetically-determined and unitary intelligence. It is a bleak and hopeless prospect for population health and health equity if we view human capability in this way. Health literacy is a practical intervention target for both of the education and public health fields, providing hope for the empowerment of people to ultimately improve population health and well-being. With respect to ageing, goals of research in this area, including this thesis, are to better understand how to prevent decline in health literacy skills and how to better design health communication and services to suit the health literacy skills of the public. Ideally, research in this area should inform clinical and public health strategies to support healthy ageing through reducing cognitive and literacy barriers to achieving good health among older adults.

12.4 Limitations

There are several important limitations of this PhD research to take into account when interpreting this thesis as whole. They are discussed in this section.

12.4.1 Non-response and attrition in the ELSA

The ELSA was sampled from the Health Survey for England, which was intended to be representative of the English population in basic sociodemographic characteristics such as age, gender, and socioeconomic status. However, study non-response, if not random, has the potential to reduce the generalisability of findings to the underlying population that was sampled from (i.e. the external validity). The response rate to the first wave of ELSA in 2002 was 67% (Marmot et al., 2003). Most non-respondents were those who declined to participate, although about 3% of eligible respondents did not participate as they were too ill during the fieldwork period and there was no suitable proxy respondent available (Marmot et al., 2003). As a result, the ELSA sample is slightly healthier than the general population of England within the same age range. This ‘healthy participant’ effect is a common issue in observational epidemiological studies, especially in older aged samples (Golomb et al., 2012). Restriction of my analyses to only the non-proxy respondents would have heightened this ‘healthy participant’ effect, as the proxy respondents were too physically or cognitive impaired to take part in the full interview. However, there were few proxy respondents in the ELSA, and their exclusion is thought to not markedly bias effect estimates generated through the ELSA data (NatCen Social Research, 2014).

At the first wave of the ELSA in 2002, compared to the responding households, the non-responding households were (Taylor et al., 2007):

- More likely to have a 50-54 or ≥85 year old as the oldest in the household and less likely to have a 65-74 year old as the oldest in the household;
- More likely to have more than two people in the household;
- More likely to have a member of the household with a limiting long-standing illness;
- More likely to reside in the North West, West Midlands, or North Thames Health Authorities, and less likely to reside in the Northern, Yorkshire, or Trent Authorities;
- More likely to have a head of household who is classified as ‘unskilled manual’ or ‘other’, and less likely to be classified as ‘professional’ or ‘managerial’.

Consequently, the baseline ELSA sample was not perfectly representative of the target population aged ≥50 years in England. The generalisability of unweighted analyses may be affected, if the distributions of the predictor and outcome variables of interest in a given analysis are altered by the non-response of specific population subgroups. The cross-sectional and longitudinal weights, however, are a useful tool to overcome potential bias introduced by study non-response, as well as attrition (NatCen Social Research, 2014).

Because the ELSA is a longitudinal cohort study, attrition over time, if non-random in the sample, also represents a potential source of bias. If the reason for study drop-out is also related to the predictor or outcome variables of interest in a given analysis, then effect estimates might end up being biased due to study attrition. The key factors associated with drop-out in my studies were older age, lower educational attainment, lower net non-pension wealth, and having worse health. These factors, unfortunately, were also predictors of low or declining health literacy, as shown in the descriptive results of the empirical chapters. As a result, the associations that I observed between these factors and health literacy decline are likely to underestimate the magnitudes of the true associations, as the lower ends of the distributions of the variables would have been missing in my analytical samples. Again, the longitudinal weights are a useful tool to account for differential study attrition (NatCen Social Research, 2014). I utilised the longitudinal study weights for Studies 3 and 5, as these two analyses were missing a significant proportion of data, to improve the population representativeness and reduce the potential for bias in these analyses.

12.4.2 Missing data

There were missing data on certain variables among the respondents who completed the ELSA data collection. Any variable that is missing less than 5% of observations is considered to be missing a negligible amount of data (Rothman & Greenland, 2008). Reassuringly, most variables that were missing data were missing a negligible number of observations, with most missing less than 1% of observations. However, there were some notable exceptions. In Studies 4 and 5, which predicted health behaviours, 5% to 10% of data on net non-pension wealth were missing. The data were not missing at random, with observations being missing predominantly from the poorer wealth quintiles. Adults with lower net non-pension wealth were consequently under-represented in these analyses. As a result, the associations with net non-pension wealth might underestimate the true magnitudes, as the study participants with low net non-pension wealth were less likely to engage in each of the behaviours. In Study 5, use of longitudinal population-based weights helped to correct any biased estimates due to missing wealth data.

The other notable source of missing data was for the self-completion questionnaire. The self-completion questionnaire was completed alone and mailed back through the post, and many ELSA participants did not return it. This affected the analysis in Study 3, as the data on Internet use and social engagement came from the self-completion questionnaire. When all of waves 2 through 5 were taken together, 20% of the eligible sample was missing self-completion data. These missing data were addressed through use of longitudinal weights to ensure that the sample was representative of the target population, despite any missing data, non-response, or attrition. Missing self-completion questionnaire data also affected the analysis in Study 5, as the data on fruit and vegetable intake and alcohol consumption came from this questionnaire. When waves 3 through 6 were taken together, 20% of participants were missing data on fruit and vegetable intake (which was not assessed at wave 2); when waves 2 through 6 were taken together, 25% were missing data on alcohol consumption. These missing data in Study 5 were dealt with in the same way as in Study 3, using longitudinal weights to help ensure representativeness, although the extent of any bias that missing data may have introduced would be difficult to accurately quantify.

12.4.3 Health literacy measurement methods

Health literacy was assessed using a validated four-item measure developed by the OECD and Statistics Canada for the IALLS, an international literacy survey (Thorn, 2009). The measure was developed based on a theoretical framework that defines literacy as skills to complete goal-based tasks, in this case, in a health-related setting. Unfortunately, although the individual measure was validated as part of the IALLS, the validation data for the individual measure were not available. The measure does have good face validity, as it comprises four basic reading comprehension questions that one should be able to answer correctly in order to take the medication properly. It is associated with risk of all-cause mortality in order adults, emphasising its predictive capability for important health outcomes (Bostock & Steptoe, 2012). However, it does not assess prose literacy, information navigation, or numeracy, other important skills for health self-management. It is a measure of functional health literacy, and does not account for the other domains of health literacy including communicative and critical health literacy. Therefore, the results of this thesis only apply to functional health literacy skills involving reading comprehension and active learning of new health information.

The health literacy measure used in this thesis was limited in that it had a narrow four-point range and a marked ceiling effect, where over two-thirds of the study sample scored 4/4 items correct on the scale at both time points; this is a common problem in functional health literacy measures (Davis et al., 1993; Parker et al., 1995). Few participants declined by more than one point on the measure, so I could not examine declines of varying magnitudes or from different starting points. Most people who declined began with three or four items correct. I also could not examine non-linear change in health literacy score, as the ELSA only has health literacy data at two time points, and I could not examine change over a period longer than the six-year follow-up between the two time points. It is unknown whether health literacy declines during ageing in a linear fashion over time, or whether there is a threshold beyond which health literacy dips at specific critical (yet unknown) points in time.

12.4.4 Cognitive function measurement methods

The cognitive battery in the ELSA included several useful measures for my analysis. The measures included in the battery were validated and previously used measures in other studies of ageing (Banks et al., 2006; MRC CFA Study, 1998). They represented cognitive functions that are important for everyday functioning, that are known to be sensitive to ageing-related decline, and were measured in a way to prevent ceiling or floor effects (Banks et al., 2006). However, I did not use the cognitive function measures of mental processing speed or prospective memory, as the measures were not independent of literacy. Mental processing speed has previously been strongly correlated with performance on tests of functional health literacy; prospective memory is less important for health literacy (Wolf et al., 2012). I conducted *post-hoc* sensitivity analyses adjusting for the mental processing speed measure in each of my studies, and found that its inclusion in models did not significantly affect my results. There was also no measure of reasoning in the ELSA, an important fluid cognitive function that declines with age and is also associated with health literacy (Wolf et al., 2012). If a measure of reasoning had been included in the ELSA, further degrees of the associations between health literacy and its antecedents and outcomes in my thesis might have been explained.

12.4.5 Measurement methods of other variables

The Internet use and social engagement variables in Study 3 were valuable variables that had never before been measured in a longitudinal fashion alongside both of health literacy and cognitive function data. However, they were not measured perfectly. The variable for Internet use was binary, assessing whether or not someone had used the Internet at each wave. There was no indication of frequency of use, the types of websites that people had accessed, or the purpose of use. This type of more fine-grained information would have been valuable to create more precise variables for the types of Internet use that people engaged in. Similarly, the variables for civic, leisure, and cultural engagement were somewhat vaguely defined. I had no indication of the specific activities undertaken within each domain or their frequency. If I had more precise measures of the types of activities within each domain, I could have separated the measures for each domain into more mentally active and passive activities to gain better measures. Because the cognitive and literacy demands of the range of activities included in each measure would vary, I expect that there is a certain degree of noise in the variables for Internet use and social engagement, which would cause some non-differential misclassification of participants within categories of these variables. Consequently, my results for the associations between each of Internet use, civic activities, leisure activities, cultural activities and health literacy decline may be underestimates of the true associations with the specific activities within each domain that are mentally stimulating.

In Study 5, the variables for all of weekly MVPA, daily fruit and vegetable intake, non-problematic drinking, and smoking were based on self-reported measures. Self-reports of health behaviour are a concern as they may introduce recall error and recall bias into results. Recall error is a simple error in responding due to imperfect recall; it is assumed to occur roughly equally across a study population and has the effect of adding noise to estimates and biasing them to the null (Rothman & Greenland, 2008). Especially given that all four of the health behaviours were assessed multiple times by self-report, there is inherently some degree of recall error present in the results of this study, as no person has perfect recall of their past behaviour. If recall error occurring randomly across the study population was the only issue with reporting of health behaviours in this study, then all of my effect estimates will be underestimates of the true associations.

Recall bias, on the other hand, occurs when reporting or recall of a variable of interest in the study population is differential across analytic subgroups (Rothman & Greenland, 2008). In my study, the concern for recall bias is if reporting of the health behaviours is differential according to health literacy level. The potential outcomes of recall bias would depend on the direction of the true association, and whether erroneous reporting results in a systematic over-estimate or under-estimate of the true level of the health behaviour within each category of health literacy. These potential outcomes were outlined in more detail in the Discussion of Study 3. Unfortunately, to the best of my knowledge, there have been no validation studies examining the accuracy of self-reported health behaviours according to health literacy level of participants, so I cannot make an informed assessment of the potential effect of recall bias in my results. My suspicion is that adults with low health literacy more often erroneously report health behaviours than those with health literacy (recall error), but that their estimates are not necessarily systematically higher or lower (recall bias).

12.5 Future research

This thesis opens up several areas for future inquiry in the fields of ageing and health literacy. The relationship between cognitive ageing and health literacy requires further research, ideally using data from multiple time points over a longer follow-up period than mine. The threshold beyond which typical cognitive ageing might affect functional literacy skills remains to be elucidated. My research indicates that there is an effect of non-pathological cognitive ageing on literacy skills, rather than limitations only being introduced at a point of cognitive impairment. The potentially reciprocal ways in which specific cognitive and literacy skills may develop across the life course, and their antecedents, require further investigation. The role of early life learning factors, including the home and school environments, in determining functional health literacy in later life should be investigated in the future using birth cohort follow-up data. Future research could also examine the other domains of health literacy, in addition to the basic ‘functional’ health literacy skills that were examined in this thesis. The changes that may occur in ‘communicative’ and ‘critical’ health literacy during ageing have never been investigated. However, these constructs first require more refinement in both definition and measurement before they can be properly considered as research outcomes.

Future research on the predictors of later-life functional health literacy should include more specific measures of Internet use and social engagement. The specific types, frequencies, and durations of Internet use over time should be measured (e.g. the websites visited, the reasons for use, and what was learned from use). The role of health literacy as a predictor of Internet technology use is also an interesting question; health literacy might contribute to health inequalities through determining who can access and use online information resources (Kobayashi & Smith, 2015; Viswanath et al., 2012, 2013). Specific intellectually stimulating social engagement activities should also be measured, rather than the broad domains of ‘civic’, ‘leisure’, or ‘cultural’ activities. My results, taken with previous evidence in this area, indicate that intellectually stimulating activities involving the learning of novel skills might promote cognitive function and health literacy among older adults. The best way to approach these questions may be using randomised, experimental methods to assess the effects of different technological and social conditions that might help to promote health literacy and general literacy skills.

My results indicate that functional health literacy has a relatively minor influence on health-promoting lifestyle behaviours. However, my results were limited by the self-reported health behaviour measures and are likely subject to recall error, which would have attenuated any real association to the null. In future, better measures of physical activity (such as objective accelerometer measurements), fruit and vegetable intake and alcohol consumption (such as from a validated food frequency questionnaire or from a diary, rather than a retrospective questionnaire) would help with the estimation of these associations with better precision. The pathways through which health literacy affects some health behaviours also require further investigation. Previous research indicates that health literacy acts via improving self-efficacy for behaviour, an effect requiring confirmation. With respect to cancer screening, the decision-making processes and preferences about screening participation that adults with high versus low literacy go through are unknown. Better understanding of these processes would help to identify areas where screening programmes can develop targeted interventions to support engagement and decision-making among those with low literacy skills. Overall, given that health literacy is markedly socially graded, as were the health behaviours examined in this thesis, the degree to which health literacy is a mediator of social inequalities in health behaviours and outcomes requires further investigation.

An important area for future research is the development and evaluations of interventions to improve health literacy among older adults. This population sub-group lacks the opportunities for formal education that younger generations have, while being burdened with a relatively high prevalence of low health literacy. Community health education programmes or cognitive training programmes, such as game-based learning using digital technologies, may be effective to improve health literacy skills (Chan et al., 2014), but would be resource-intensive to deliver at a population level. Interventions embedded into health systems, such as interactive decision aids that are targeted at older adults with low health literacy or one-on-one patient navigation strategies that would allow older adults to learn about health issues and actively participate in decision-making would likely be more feasible as health literacy interventions for older adults (S. K. Smith, et al., 2010; Shankleman et al., 2014; Horne et al., 2015)

An exciting intervention currently underway is the OPHELIA project, which aims to identify local health literacy needs and co-develop appropriate interventions with community stakeholders (Batterham et al., 2014). In collaboration with the WHO, the OPHELIA project has developed a health literacy toolkit for low- and middle-income countries to empower communities and strengthen health systems (WHO Regional Office for South-East Asia, 2015). Although a slight disadvantage of the OPHELIA is that its HLQ measure has not yet been compared with existing measurement tools, it has the advantage of recognising the contextual aspect of health literacy. Among other things, the OPHELIA project aims to prioritise local wisdom, culture, and systems, focus on equity in health outcomes, and respond to the varying and changing health literacy needs of individuals and communities (Batterham et al., 2014). Further research to validate the OPHELIA's HLQ instrument against existing functional health literacy measurements (e.g. the TOFHLA) will be valuable. The degree to which OPHELIA will be taken up by communities across high-, middle-, and low-income countries, as well as its potential effectiveness, remains to be seen.

With the new HLS-EU-Q and HLQ instruments that assess comprehensive domains of health literacy through self-report, we may see a shift towards greater recognition of self-assessed health literacy in this field. Self-report measures have the potential to account for the contextual nature of literacy, whereby people's health literacy needs vary according to their health needs and life circumstances (Kickbusch et al., 2013). While health literacy assessed by the HLS-EU-Q and the TOFHLA tends to show similar relationships with sociodemographic factors, there should be further research to assess the consistency of self-report measures against objective measures. Qualitative research will also be valuable to better understand how life circumstances affect people's health literacy needs. The tension between objective and self-report measures of health literacy needs to be resolved, as they have potential to be used in concert to better understand the construct of health literacy.

12.6 Concluding remarks

This thesis has demonstrated that functional health literacy, measured as reading comprehension of a medicine label, declines over time during ageing in about one-fifth of English adults aged 52 years and over. Decline appears to begin around 65 and accelerates with age, and is associated with social inequalities. However, ageing-related health literacy decline was not inevitable. Consistent Internet use and social engagement, particularly in cultural activities, appeared to help promote the maintenance of health literacy during ageing. Older adults who had good cognitive functioning at baseline and who did not decline in cognitive function over time were also less likely to decline in health literacy performance. Health literacy was positively associated with participation in colorectal cancer screening, an effect that was explained by cognitive functioning around the time of screening. Health literacy was also positively associated with the long-term maintenance of weekly physical activity. This result was independent of cognitive function, physical health, and social factors. In all, the results of this thesis indicate that health literacy is a resource that socially advantaged adults gain and maintain through specific social practices, and can use to further improve and protect their health.

I believe that this thesis makes an important contribution to the health literacy field. This thesis made use of longitudinal data on health literacy that were collected alongside rich sociodemographic, social, cognitive, and health-related data in a population-based cohort study of ageing in England. Several insights into the nature of ageing-related health literacy decline, and its potential causes and health behavioural outcomes were identified in this thesis. This thesis also highlights problems surrounding the definition and measurement of health literacy, which plague this research field. The field needs to be more consistent in its definitions and operationalisations of health literacy, and researchers must reach a consensus over whether health literacy is separate from cognitive functions or the health actions comprising health promotion. I hope that this debate can be resolved, so that the health outcomes of low literacy can be better understood and better addressed. Given that literacy is inherently context specific, the debate may never end, but rather may require different approaches across different people, places, and time. I look forward to being a part of this academic discourse in helping the health literacy field to evolve in the future.

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Appendices

Appendix 7.1 Published paper in J Gerontol B Psychol Sci Soc Sci

Kobayashi, L.C., Wardle, J., Wolf, M.S., & von Wagner, C. (2014). Aging and functional health literacy: a systematic review and meta-analysis. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, doi:10.1093/geronb/gbu161

New Directions in Aging

Aging and Functional Health Literacy: A Systematic Review and Meta-Analysis

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Objectives. To review the evidence on the association between age and limited health literacy, overall and by health literacy test, and to investigate the mediating role of cognitive function.

Method. The Embase, MEDLINE, and PsycINFO databases were searched. Eligible studies were conducted in any country or language, included participants aged ≥50 years, presented a measure of association between age and health literacy, and were published through September 2013.

Results. Seventy analyses in 60 studies were included in the systematic review; 29 of these were included in the meta-analysis. Older age was strongly associated with limited health literacy in analyses that measured health literacy as reading comprehension, reasoning, and numeracy skills (random-effects odds ratio [OR] = 4.20; 95% confidence interval [CI]: 3.13–5.64). By contrast, older age was weakly associated with limited health literacy in studies that measured health literacy as medical vocabulary (random-effects OR = 1.19; 95% CI: 1.03–1.37). Evidence on the mediating role of cognitive function was limited.

Discussion. Health literacy tests that utilize a range of fluid cognitive abilities and mirror everyday health tasks frequently observe skill limitations among older adults. Vocabulary-based health literacy skills appear more stable with age. Researchers should select measurement tests wisely when assessing health literacy of older adults.

Key Words: Adults—Aging—Cognition—Health literacy—Measurement.

LIMITED functional health literacy among adults is a major public health problem. Functional health literacy is defined as an individual's capacity to obtain, process, and understand basic health information and services sufficiently to make appropriate health decisions and will be used interchangeably with the term "health literacy" in this review (Institute of Medicine, 2004). Limited health literacy is of particular concern among older adults, who often have increased needs for health information and services to maintain their health and well-being. National literacy surveys indicate that more than 70% of adults aged older than 65 years in North America lack the basic health literacy skills required for successful interactions with health systems (Canadian Council on Learning, 2008; Kutner, Greenberg, Jin, & Paulsen, 2006). Outcomes of limited health literacy among older adults include incorrect taking of prescription medication, poor chronic disease management, low use of preventive health services, and increased risk of overall mortality (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Sudore et al., 2006b).

The nature of the association between aging and health literacy is unclear. Functional health literacy skills reflect, at least in part, the cognitive abilities used to manage health (Federman, Sano, Wolf, Siu, & Halm, 2009; Reeve & Basalik, 2014; Wolf et al., 2012). "Fluid" cognitive abilities such as verbal fluency, working memory, and reasoning are essential to health literacy skills and undergo mild decline during aging in the absence of dementia as early as mid-adulthood, whereas "crystallized" abilities such as generalized knowledge and vocabulary are more stable with age (O'Carroll, 1995; Singh-Manoux et al., 2012). Therefore, performance on health literacy tests that require the use of fluid cognitive abilities in the context of medical and health-related information may decline with age (e.g., the Test of Functional Health Literacy in Adults [TOFHLA] or the Newest Vital Sign [NVS]; Parker, Baker, Williams, & Nurss, 1995; Weiss et al., 2005), whereas tests that assess health literacy as medical vocabulary may show little decline in performance with age (e.g., the Rapid Estimate of Adult Literacy in Medicine [REALM]; Davis et al., 1993).

If health literacy skills represent the functional use of cognitive abilities in health contexts, then certain health literacy skill sets, but not necessarily others, would be expected to decline with age. Furthermore, any association between age

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and health literacy would be expected to be at least partly explained by cognitive aging. We hypothesized that the functional health literacy skills assessed by TOFHLA and similar tests (representing fluid cognitive abilities) would be more likely to show an inverse association with age than health literacy skills assessed by the REALM and similar tests (representing crystallized cognitive abilities). We aimed to review the evidence on the association between age and health literacy, overall and by health literacy test, and to investigate the mediating role of cognitive function.

Method

Identification of Studies

This systematic review and meta-analysis was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement recommendations (Moher, Liberati, Tetzlaff, & Altman, 2009). The search strategy was developed by two reviewers following instruction from University College London librarians. The Embase, MEDLINE, and PsycINFO databases were used to search for relevant articles conducted in any country or language and published in English through September 30, 2013 (see the Supplementary Table 1 for the complete electronic search strategy). Studies were included in the narrative synthesis if health literacy was measured using an objective instrument (the TOFHLA, REALM, or NVS; see Table 1) and if a measure of association between age and health literacy was presented with an associated statistical significance level. Studies were excluded if the study population did not include adults aged ≥50 years or if the study population entirely comprised individuals with diagnosed cognitive or mental health impairments, as these studies would be restricted in participant variance of cognitive ability. Studies were included in the meta-analysis if odds ratio (OR) and 95% confidence interval (CI) for limited health literacy by age (≥65 vs <65 years; if this comparison was not available, then similar age cutoffs were acceptable) were computable from the presented results.

Article Screening and Data Abstraction

Returned article titles and abstracts were screened and those that did not meet the exclusion criteria were downloaded in full text. The methods and results sections of the downloaded articles were then screened for final inclusion. When multiple articles on the same study population were eligible, either the article that was published first or the one that presented a multivariable-adjusted measure of association was selected. Reference lists of included articles were hand-searched for additional references. One reviewer (L. C. Kobayashi) performed the initial search, screening, and data extraction. The second (C. von Wagner) checked all included articles and extracted data. The two authors were in 100% agreement over the articles included and data extracted. The data items extracted were: (a) study design, country, and language of

Table 1. Characteristics of the Health Literacy (HL) Tests: The "Test of Functional Health Literacy in Adults" (TOFHLA), the "Newest Vital Sign" (NVS), and the "Rapid Estimate of Adult Literacy in Medicine" (REALM)

Test	Year	Measure	Skills assessed	Scoring	Short form	Adaptations
TOFHLA	1995	Common medical materials (e.g., prescription labels) followed by comprehension questions using the Cloze procedure—a technique that omits every 5–7 words in a sentence 22 min to administer	Reading comprehension (50 items) Numeracy (17 items)	0–59: inadequate HL 60–74: marginal HL 75–100: adequate HL <75: limited HL	S-TOFHLA	UK-TOFHLA translations: Korean Serbian French Italian German Portuguese
NVS	2005	A 6-item test based on the ability to read and apply information from an ice cream nutrition label 3 min to administer	Reading comprehension Numeracy	<2: greater than a 50% chance of having marginal or inadequate HL 2–4: possibility of limited HL >4: adequate HL		Translation: Turkish
REALM	1991	66 medical words ranging from "fat," "flu", and "pill" to "obesity," "osteoporosis," and "impetigo," which the participant is instructed to read out loud 2–3 min to administer	Word recognition Pronunciation	Reading level according to score: 0–18: ≤3rd grade 19–44: 4–6th grade 45–60: 7–8th grade 61–66: ≥9th grade <61: limited HL	REALM-SF REALM-R	Translation: Turkish

conduct, source of the study population, inclusion and exclusion criteria, sample size, and participation rates; (b) age statistics of the study population, including mean, median, and range; (c) the health literacy instrument used and health literacy score/level of the study population by age in categories defined by the study authors, if given; and (d) the measure of association between health literacy and age with corresponding *p* values, the statistical test(s) used, and confounding variables adjusted for, including cognitive function (if applicable).

We followed the recommendations in the Cochrane handbook to develop risk criteria based on existing guidelines (The Cochrane Collaboration, 2011; von Elm et al., 2007; Wells et al., n.d.): (a) study designs – with prospective studies ranked as having lower risk of bias; (b) participation rate – those with higher participation rates ranked as having lower risk of bias; and (c) adjustment for confounding. All eligible analyses were cross-sectional and only half reported participation rates; we therefore categorized risk of bias according to the third criterion only.

Statistical Analysis

As a scoping summary to aid the narrative review, the percentage of studies detecting a statistically significant association between age and health literacy was calculated for all studies combined by health literacy test, by participation rate, and by whether they reported an adjusted measure of association. For the meta-analysis, the outcome was a pooled OR and 95% CI for the association between age and limited health literacy. The age cutoff of 65 years was chosen as it is useful in terms of policy purposes (e.g., it is the age of retirement in several Western countries) and it was a common cutoff used in studies in an early literature scan. "Limited" health literacy was the outcome (Table 1). It represents a clinically significant cut point where individuals begin to have difficulty with everyday health tasks and where the risks of several adverse health outcomes begin to increase (Davis et al., 2006; Lee, Arozullah, Cho, Crittenden, & Vicencio, 2009; Peterson, Dwyer, Mulvaney, Dietrich, & Rothman, 2007; Scott, Gazmararian, Williams, & Baker, 2002; Sudore et al., 2006a).

Standardized effect size measures (e.g., Cohen's *d* or Hedge's *g*) were not used for this analysis. Meta-analytic techniques pooling these measures would assume that between-study variations in the standard deviations for mean health literacy scores are due to scale differences, rather than to any true variability in health literacy test performance between study populations (Greenland & O'Rourke, 2008; The Cochrane Collaboration, 2011). This assumption cannot be made in the context of our meta-analysis, given that the varying sociodemographic compositions of individual study populations including varying age ranges, countries, and languages would likely give rise to variability in health literacy performance between study populations.

When effect estimates were not reported as ORs for limited health literacy, but data were sufficient to compute these values (i.e., in cross-tabular format), they were transformed into ORs using Comprehensive Meta-Analysis (CMA) software (Version 2.2.064). As raw ORs cannot be meaningfully aggregated, all ORs were transformed to the natural log (lnOR) for analyses, then transformed back to OR and 95% CI for interpretation. In cases where ORs for limited health literacy could not be computed, study authors were contacted to retrieve the data in an appropriate format for data synthesis. Studies reporting mean age by categories of health literacy score ($n = 20$) were excluded from the meta-analysis as these studies treat age as the dependent variable and thus cannot produce an OR predicting health literacy. These studies were summarized narratively.

The meta-analysis was performed using fixed- and random-effects models. The random-effects model is likely to be more valid, as the true association between age and health literacy cannot be assumed equal between studies for the same reason that variability in health literacy performance across study populations must be assumed. Heterogeneity in the fixed-effects models was assessed using the Q value and Higgins and Thompson's I^2 statistics. The Q value tests whether the observed variance in effects is not greater than that would be generated by sampling error; a Q value with a corresponding $p < .05$ indicates the presence of heterogeneity and that a random-effects model is appropriate. The I^2 statistic is an estimate of the proportion of total variation in study estimates due to heterogeneity (The Cochrane Collaboration, 2011). Fixed-effects models with corresponding heterogeneity tests were ran first, followed by random-effects models. The meta-analysis was performed for all studies together and stratified by health literacy test, to test our hypothesis that study results would differ by test.

A sensitivity analysis removing one study at a time from the pooled analysis examined for influential individual studies on the overall pooled result. This technique allows for identification of particular aspects of an individual study that may skew the overall combined result. A second sensitivity analysis was performed, removing from the meta-analysis all studies using age cutoffs other than age 65. A random-effects meta-regression was performed to assess the extent to which heterogeneity in the pooled result can be related to each of the following individual study characteristics: health literacy test, health status of study population, country of study, language of study, and participation rate. Publication bias was assessed using the classic fail-safe N method, which is the theoretical number of unpublished studies with a null result that would be required to render the calculated pooled result null. A funnel plot of standard error by lnOR was also generated, and Duval and Tweedie's "trim and fill" method used to estimate the number of studies missing due to publication bias. This method provides an imputed estimate of the pooled effect size after publication bias is taken into account (Greenland & O'Rourke, 2008).

Statistical analyses were conducted using CMA (Biostat, Englewood, NJ) and StataSE 13.1 (StataCorp, College Station, TX).

Results

Search Results

A total of 70 analyses in 60 studies with data on 33,379 participants were included in the narrative review. A total of 29 analyses with data on 18,492 participants were included in the meta-analysis (Figure 1; Supplementary Table 2).

Overview of Included Studies

Countries of origin.—Studies were conducted in nine different countries and languages (Supplementary Table 2). The predominant country of study was the United States and the predominant language English. All manuscripts were written in English.

Study designs and populations.—Although study designs varied, age and health literacy were analyzed cross-sectionally in all studies. Study populations were healthy, community-dwelling adults (11/60; 18%) (Adams et al., 2009; Connor et al., 2013; Federman et al., 2009; Gazmararian et al., 1999; Jackson & Eckert, 2008; Kim, 2009; McDougall et al., 2012; Roth & Ivey, 2005; Stewart et al., 2013; Sudore et al., 2006a; von Wagner et al., 2007), community-dwelling outpatients recruited in health care settings (18/60; 30%) (Aguirre, Ebrahim, & Shea, 2005; Backes & Kuo, 2012; Bains & Egede, 2011; Carthery-Goulart et al., 2009; Chew et al., 2004; Davis et al., 2006; Ferguson, Lowman, & DeWalt, 2011; Haun, Luther, & Dodd, 2012; Jovic-Vranes et al., 2009, 2011; Jovic-Vranes & Bjegovic-Mikanovic, 2012; Lindau et al., 2002; Miller et al., 2007; Mosher et al., 2012; Ozdemir, Alper, Uncu, & Bilgel, 2010; Peterson et al., 2007; Shah, West, Bremmeyr, & Savoy-Moore, 2010; Shea, Beers, McDonald, Quistberg, Ravenell, & Asch, 2004), chronic disease patients (23/60; 38%) (Armistead-Jehle et al., 2010; Cavanaugh et al., 2010;

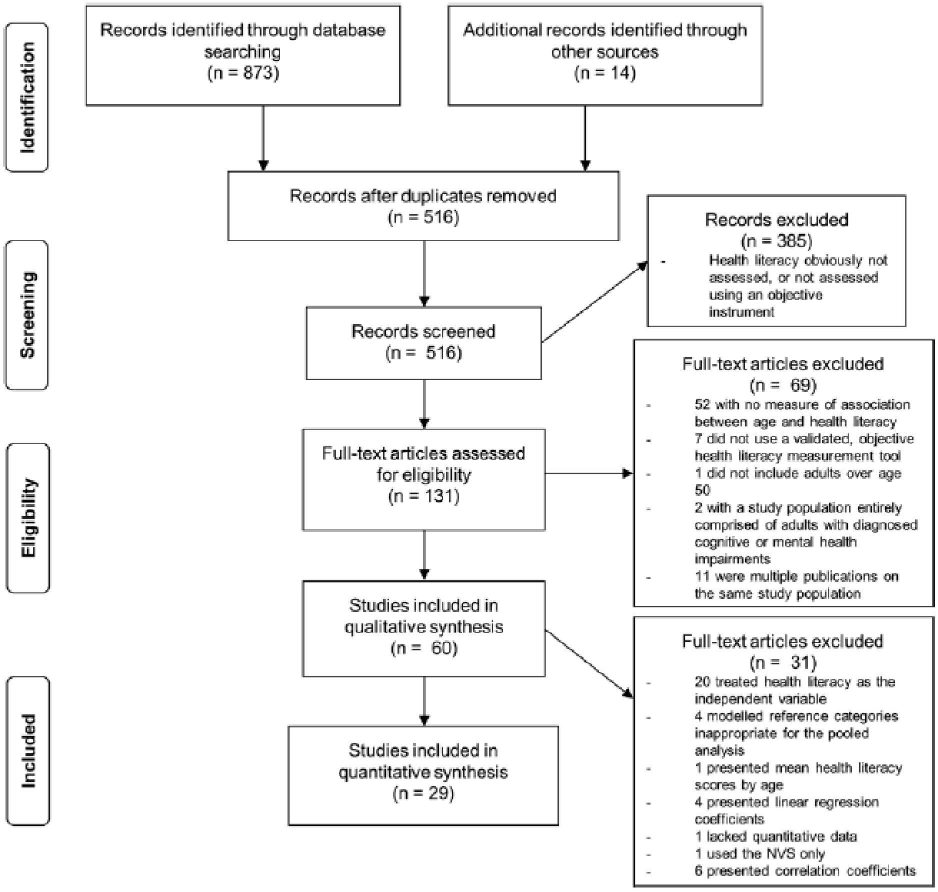

Figure 1. PRISMA flow diagram.

Colbert, Sereika, & Erlen, 2013; Cox, Bowmer, & Ring, 2011; Gordon et al., 2002; Green et al., 2011; Ibrahim et al., 2008; Juzych et al., 2008; Kalichman et al., 2000; Kirk et al., 2012; Laramee et al., 2007; Levinthal et al., 2008; Mancuso & Rincon, 2006; Mbaezue et al., 2010; Morrow et al., 2006; Nokes et al., 2007; Osborn et al., 2010; Robinson et al., 2011; Rowlands et al., 2013; Schillinger et al., 2002; Swearingen et al., 2010; Williams, Baker, Parker, & Nurss, 1998; Zhang, Li, Fong, & Thumboo, 2009), emergency department/acute care inpatients (5/60; 8%); Baker et al., 1998; Ginde et al., 2008; McNaughton et al., 2011; Morris et al., 2011; Olives et al., 2011, and a refugee population (1/60; 2%; Supplementary Table 2). Two studies had samples comprising hospital inpatients and outpatients (Downey & Zun, 2008; Walker, Pepa, & Gerard, 2010).

All studies used "convenience" samples except for two that aimed to recruit samples representative of the general population (Adams et al., 2009; von Wagner, Knight, Steptoe, & Wardle, 2007). Studies sampling from emergency room patients and acute care hospital inpatients excluded those who were too ill or distressed to participate. Half reported participation rates (median reported rate = 87%; range: 26%–98%). Sample sizes ranged from 44 to 3,260; eight studies had <100 participants.

Health literacy measurements.—Thirty-six studies (60%) assessed health literacy using the TOFHLA or S-TOFHLA in the original or a translated or culturally adapted version (Supplementary Table 2). Two of these (Aguirre et al., 2005; Connor, Mantwill, & Schulz, 2013) stratified their study populations by ethnicity and language (Aguirre et al., 2005) or by language (Connor et al., 2013) to give three analyses each, for a total of 40 analyses using the TOFHLA or S-TOFHLA. Twenty-six studies (43%) assessed health literacy using the REALM or one of its short forms (Supplementary Table 2). Four studies used the NVS (Adams et al., 2009; Kirk et al., 2012; Ozdemir et al., 2010; Shah et al., 2010). Three used both the TOFHLA and the REALM (Haun et al., 2012; McNaughton, Wallston, Rothman, Marcovitz, & Storrow, 2011; Walker et al., 2010), one used the REALM and the NVS (Ozdemir et al., 2010), and one used all three instruments (Kirk et al., 2012). Therefore, a total of 70 analyses were performed in the 60 studies included in the narrative review. The three separate analyses in Connor et al.'s (2013) study were collapsed by the authors for the meta-analysis, to give a total of 29 analyses in 31 studies in the meta-analysis.

Overview of Study Results

Narrative review.—Overall, 41/70 analyses (59%) observed a statistically significant inverse association between age and health literacy. This association was more frequently observed in analyses using the S-TOFHLA/TOFHLA (32/40; 80%) and NVS (3/4; 75%) than in those using the REALM (6/26; 23%); a statistically significant difference ($\chi^2(2) = 21.51$, $p < .001$). Twenty-two out of 28 (79%) analyses presenting a multivariable-adjusted measure of association between age and health literacy compared with 19/42 (45%) analyses presenting an unadjusted association observed a statistically significant inverse relationship ($\chi^2(1) = 7.69$, $p = .006$). This finding may be in part a methodological artifact, as several studies that observed a nonsignificant result in unadjusted analysis did not include age in multivariable modeling. The likelihood of observing a statistically significant result did not differ by participation rate (Kruskal–Wallis $\chi^2(1) = 0.067$, $p = .80$) or by whether a participation rate was reported ($\chi^2(1) = 0.11$, $p = .74$). Among studies that compared mean age across health literacy score categories, 6/8 (75%) that used the TOFHLA or S-TOFHLA observed that adults in lower health literacy categories had a higher mean age, compared with 3/12 (25%) studies that used the REALM ($\chi^2(1) = 4.85$, $p = .028$).

Meta-analysis.—The meta-analysis of 29 individual analyses gave an overall fixed-effects OR of 2.33 (95% CI: 2.12–2.56) for the association between older age and limited health literacy. The Q value was 274.68 ($df = 28$; $p < .0001$) and I^2 statistic was 89.81, indicating that significant heterogeneity within the fixed-effects results and that results from the random-effects model (OR = 2.56; 95% CI: 1.85–3.53) are appropriate for interpretation. Within studies using the S-TOFHLA/TOFHLA, the fixed-effects OR was 4.44 (95% CI: 3.89–5.06). The Q value was 77.70 ($df = 18$; $p < .0001$) and I^2 statistic was 76.83, indicating significant heterogeneity and that results from the random-effects model (OR = 4.20; 95% CI: 3.13–5.64) are again appropriate for interpretation. Within studies using the REALM, the fixed-effects OR was 1.20 (95% CI: 1.05–1.37), with a Q value of 9.40 ($df = 9$; $p = .40$) and I^2 statistic of 4.26, indicating that heterogeneity may not be important. The random-effects OR was 1.19 (95% CI: 1.03–1.37). In this instance, the fixed- and random-effects ORs were negligibly different; we select the random-effects OR for interpretation to be conservative and consistent with reporting. Figure 2 shows a forest plot and individual study statistics for the random-effects meta-analyses.

A sensitivity analysis removing one study at a time showed that no individual study exerted significant influence over the pooled result. The second sensitivity analysis removing all studies using age cutoffs other than age 65 showed similar results to the main analysis. In this analysis, the random-effects OR for limited health literacy was 4.23 (95% CI: 2.86–6.27) within studies using the S-TOFHLA/TOFHLA and was 1.31 (95% CI: 1.10–1.57) within studies using the REALM.

Meta-regression.—A random-effects meta-regression model showed that health literacy test was influential on the pooled estimate (Table 2). Studies using the S-TOFHLA/

Group by Health literacy test	Study name	Age comparison	Statistics for each study: Odds ratio	Lower limit	Upper limit	Z-Value	p-Value
REALM	Lindau	50+ vs. <50	0.715	0.268	1.913	-0.667	0.504
REALM	Ferguson	60+ vs. <60	1.344	0.646	2.797	0.791	0.429
REALM	Bains	65+ vs. <65	0.952	0.530	1.710	-0.165	0.869
REALM	Cox	65+ vs. <65	0.612	0.170	2.205	-0.750	0.453
REALM	Kirk2	65+ vs. <65	1.288	0.723	2.297	0.859	0.390
REALM	Ozdemir	65+ vs. <65	0.707	0.210	2.381	-0.560	0.575
REALM	Shea	65+ vs. <65	1.452	1.182	1.784	3.547	0.000
REALM	Walker2	65+ vs. <65	0.592	0.160	2.184	-0.788	0.431
REALM	Sudore	77+ vs. <77	1.050	0.841	1.311	0.430	0.667
REALM	Haun2	80+ vs. <80	1.185	0.517	2.716	0.401	0.688
REALM			1.185	1.025	1.370	2.293	0.022
TOFHLA	Mancuso	42+ vs. <42	5.661	2.195	14.599	3.587	0.000
TOFHLA	Jovic-Vranes 2009	44+ vs. <44	4.860	2.410	9.800	4.418	0.000
TOFHLA	Geltman	45+ vs. <44	5.413	2.636	11.118	4.599	0.000
TOFHLA	Downey	53+ vs. <53	3.329	1.902	5.828	4.210	0.000
TOFHLA	Colbert	55+ vs. 20-54	0.854	0.190	3.834	-0.206	0.837
TOFHLA	Aguirre	65+ vs. <65	20.761	9.864	43.694	7.989	0.000
TOFHLA	Carthery-Goulart	65+ vs. <65	2.779	1.562	4.947	3.475	0.001
TOFHLA	Chew	65+ vs. <65	3.700	1.695	8.076	3.285	0.001
TOFHLA	Connor	65+ vs. <65	10.804	6.737	17.326	9.877	0.000
TOFHLA	Ginde	65+ vs. <65	1.736	0.913	3.298	1.684	0.092
TOFHLA	Jovic-Vranes 2011	65+ vs. <65	4.250	3.261	5.539	10.703	0.000
TOFHLA	Kirk1	65+ vs. <65	2.427	1.483	3.971	3.529	0.000
TOFHLA	Laramee	65+ vs. <65	3.510	2.184	5.641	5.188	0.000
TOFHLA	Morris	65+ vs. <65	4.538	1.912	10.770	3.429	0.001
TOFHLA	von Wagner	65+ vs. <65	6.300	3.304	12.014	5.589	0.000
TOFHLA	Walker1	65+ vs. <65	1.339	0.396	4.521	0.470	0.638
TOFHLA	Haun1	80+ vs. <80	7.132	3.073	16.554	4.573	0.000
TOFHLA	Federman	85+ vs. 65-69	1.420	0.667	3.027	0.909	0.363
TOFHLA	Gazmararian	85+ vs. <85	8.620	5.552	13.384	9.596	0.000
TOFHLA			4.204	3.131	5.644	9.550	0.000

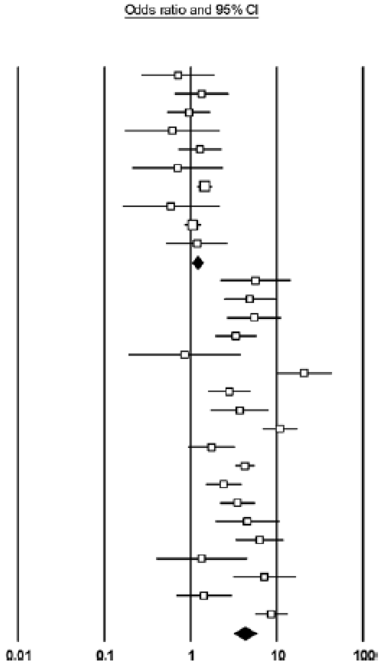

Figure 2. Forest plot of random-effects pooled odds ratios for the association between older age and limited health literacy, stratified by health literacy test.

Table 2. Random-Effects Meta-Regression for Influence of Study Characteristics on Pooled Result

Study characteristic	Coefficient	Standard error	95% CI	*p* Value
Health literacy test				
REALM	—	—	—	—
TOFHLA/S-TOFHLA	4.44	1.34	1.75, 5.53	<.0001
Health status of study population				
Healthy, community dwelling	—	—	—	—
Chronic disease patients	0.57	1.40	0.29, 1.13	.11
Community-dwelling outpatients	0.92	1.32	0.53, 1.60	.77
Acute care patients	0.46	1.54	0.20, 1.06	.07
Adjusted for socioeconomic or cognitive factors				
No	—	—	—	—
Yes	1.13	0.79	0.64, 1.99	.68
Country of study				
United States	—	—	—	—
Other	0.92	1.34	0.52, 1.65	.84
Language of study				
English	—	—	—	—
Other	0.94	1.34	0.53, 1.67	.84
Participation rate reported				
No	—	—	—	—
Yes	1.21	1.26	0.76, 1.92	.42

Notes. CI = confidence interval; REALM = Rapid Estimate of Adult Literacy in Medicine; TOFHLA = Test of Functional Health Literacy in Adults. Regression coefficients indicate the estimated change in odds ratio for the variable category contrasted with the reference group, indicated by the dashed cells.

TOFHLA had, on average, an OR of 4.44 (95% CI: 1.75–5.53) higher than that of studies using the REALM to assess health literacy. The health status of study populations, whether socioeconomic status and/or cognitive impairment was adjusted for, country of study, language of study, and participation rate were not modifiers of the relationship between age and health literacy (Table 2). The τ^2 statistic, which indicates the amount of residual between-study variance after accounting for these variables, was 0.22.

Publication bias.—The classic fail-safe *N* was 2,080, indicating that this number of theoretically unpublished studies with null results would have to exist in order to attenuate the overall pooled effect estimate to the null. The funnel plot showed reasonable symmetry, although studies with larger lnOR values tended to have larger standard errors. Duval and Tweedle's "fill and trim" method imputed four additional studies to produce symmetry in the graph (Figure 3). The imputed overall pooled random-effects OR that takes publication bias into account was 3.01 (95% CI: 2.19–4.13). This imputed OR is more extreme but not significantly different to the original overall random-effects OR of 2.56 (95% CI: 1.85–3.53).

The mediating role of cognition.—Only five studies adjusted for cognitive function when assessing the relationship between age and health literacy (Armistead-Jehle, Cifu, Wetzel, Carne, & Klanchar, 2010; Chew, Bradley, Flum, Cornia, & Koepsell, 2004; Gazmararian et al., 1999; Levinthal, Morrow, Tu, Wu, & Murray, 2008; Morrow et al., 2006). Two of these studies adjusted for the fluid cognitive abilities of speech comprehension, processing speed, working memory, and listening span, along with visual and auditory function (Levinthal et al., 2008; Morrow et al., 2006). Data from these studies were not available for inclusion in the meta-analysis but provide important insights into the influence of cognitive function on health literacy skills during aging. Levinthal and colleagues (2008) observed that age was no longer significantly associated with health literacy after accounting for cognitive and sensory variables in their linear regression model predicting S-TOFHLA score. By contrast, Morrow and colleagues (2006) observed that age differences in health literacy were explained by educational differences within their sample and not by cognitive or sensory ability in their regression model predicting S-TOFHLA score. However, each cognitive ability assessed was a strong predictor of S-TOFHLA score, regardless of age (βs ranged from 0.39 to 2.08, all with $p < .001$). The three other studies adjusted for age-related cognitive impairment as measured by the Mini-Mental State Examination (MMSE) and Mini-Cog but did not observe complete attenuation of the association between age and TOFHLA-assessed health literacy (Armistead-Jehle et al., 2010; Chew et al., 2004; Gazmararian et al., 1999). One study observed some attenuation of the age–health literacy association from OR = 5.9 (95% CI: 2.8–12.5) to OR = 3.7 (95% CI: 1.7–8.1) after adjustment for cognitive impairment, educational attainment, and employment status (Chew et al., 2004). The

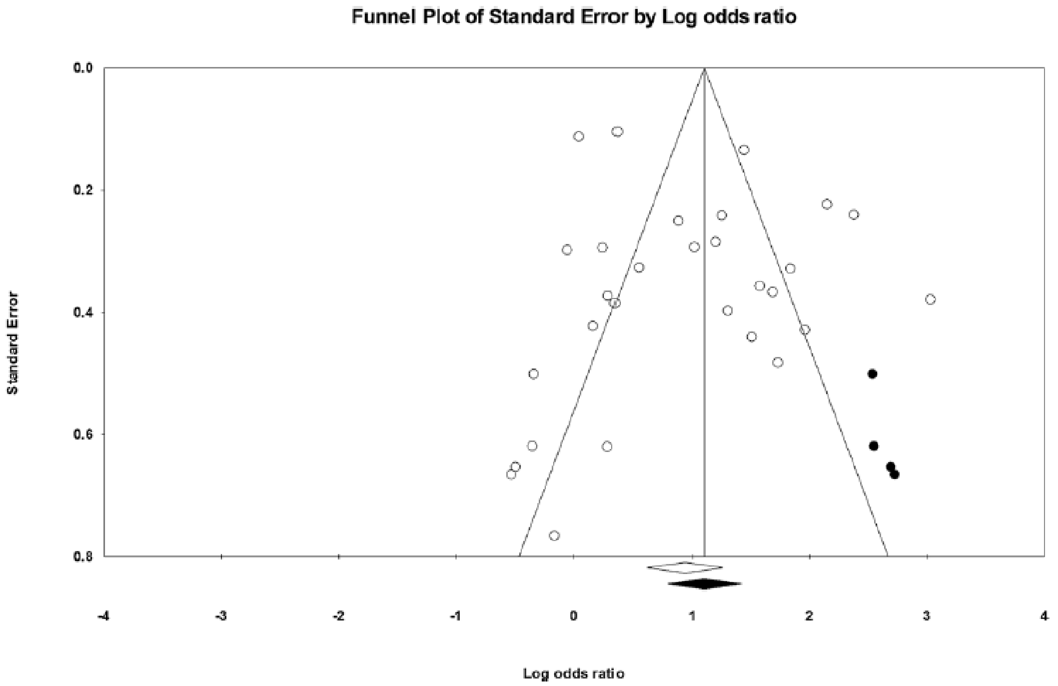

Figure 3. Funnel plot of standard error by log odds ratio to assess publication bias, with studies imputed using the "trim and fill" method shown in black.

degree of attenuation of the age–health literacy relationship by cognitive impairment in the other two studies is unascertainable, as neither presented the crude measures of association prior to adjustment for cognitive impairment.

Discussion

Our findings are consistent with a 2005 review on the prevalence of limited health literacy in the United States, which observed older adults to be more likely to have limited health literacy (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). In our review, older age was strongly associated with having limited health literacy in studies that assessed health literacy as reading comprehension, reasoning, and numeracy skills, using the TOFHLA or S-TOFHLA. Older age was weakly associated with limited health literacy in studies that assessed health literacy as medical vocabulary, using the REALM. These findings suggest that aging-related health literacy decline primarily occurs with skills requiring fluid, rather than crystallized cognitive abilities. However, evidence on the cognitive processes that may explain health literacy decline was limited, with one study but not another indicating that fluid cognitive abilities explain age differences in S-TOFHLA scores.

The Role of Cognition

The role of cognition in the apparent aging-related health literacy decline is not yet well understood. Although MMSE score and S-TOFHLA-assessed health literacy have been strongly positively associated among older adults, independent of age (Baker et al., 2002; Dahlke, Curtis, Federman, & Wolf, 2014; Federman et al., 2009), age-related cognitive impairment according to the MMSE did not explain why health literacy tended to decrease with increasing age in the few studies reviewed here. It may be that milder degrees of cognitive impairment than those detectable by the MMSE affect functional health literacy skills.

The two studies that assessed the mediating roles of fluid cognitive and sensory abilities in the relationship between age and health literacy showed conflicting results (Levinthal et al., 2008; Morrow et al., 2006). However, based on the bodies of evidence showing strong relationships between fluid cognitive ability and functional health literacy (Murray, Johnson, Wolf, & Deary, 2011; Reeve & Basalik, 2014; Wolf et al., 2012), and longitudinal declines in fluid cognitive ability during aging (O'Carroll, 1995; Salthouse, 2009; Singh-Manoux et al., 2012), it seems probable that cognitive aging plays a role in aging-related functional health literacy decline. It may also be that other factors related to cognition such as cognitive reserve also affect health literacy skills during aging. Practices that can help to improve or maintain cognition during aging such as social engagement and physical activity may help with the maintenance of health literacy skills (Sofi et al., 2011; Thomas, 2011). Longitudinal research is needed to determine the extent to which cognitive aging may explain health literacy decline, in addition to other likely processes.

Limitations

All analyses were cross-sectional and therefore could not assess the temporality of the association between aging and health literacy. The majority of studies were judged to be of a higher risk of bias, as most studies in the meta-analysis did not adjust for potential confounders. Selection bias may be present in individual studies if the reasons for nonresponse are related to age or health literacy, although the degree to which any cumulative selection bias across studies has influenced the results of this review is difficult to ascertain. Several studies excluded adults with cognitive impairment, which limited our ability to assess the role of cognitive impairment in age-related health literacy differences. Studies that analyzed health literacy score using continuous measures of association could not be included. Standardized mean difference statistics that would be used to pool continuous effect measures assume that variability in health literacy scores is due to scale differences, rather than due to true variation in health literacy across study populations, an assumption that is unlikely to be true. In these instances, study authors were contacted to obtain the data in a format useable for the purpose of this meta-analysis, with reasonable success (response from 8/16 authors). We were limited to studies published in English, although the included studies were conducted in nine different countries and languages. Finally, few studies investigated the role of cognitive abilities in age-related health literacy decline, which prevented us from drawing firm conclusions about this complex relationship. However, this meta-analysis may provide as guidance for future research into this emerging area of inquiry.

Strengths

This review adhered to the PRISMA guidelines for systematic review reporting (Moher et al., 2009) and closely followed guidelines in the Cochrane Handbook (The Cochrane Collaboration, 2011). It is the first quantitative synthesis of data on aging and health literacy that we are aware of. We excluded studies solely comprising individuals with diagnosed mental health and cognitive impairments. However, studies that included some adults with cognitive impairments were eligible, as we aimed to capture variability in cognitive ability in order to assess its mediating role in the age–health literacy relationship. We used the well-defined and clinically relevant outcome of "limited health literacy," which allowed us to examine not only whether older adults had lower health literacy than younger adults, but also how much more likely they were to be below this threshold. Although the majority of studies were judged to be of a higher risk of bias, our meta-regression analysis did not identify adjustment for socioeconomic factors or cognitive impairment, or low/nonreporting of participation rates as influential factors over the pooled point estimate.

Conclusions

Limited functional health literacy is common among older adults and may lead to disenfranchisement from access to health care services due to limitations in navigation, comprehension, and decision making. However, the theoretical understanding of health literacy and aging has been hampered by the use of instruments assessing a variable range of constructs as "health literacy," inconsistent measures of cognitive ability across the few studies examining cognitive processes, and a lack of longitudinal research.

Careful methodological decisions must be made in future research. Even though the TOFHLA, NVS, and REALM all assess functional skills, performance on these tests shows differential associations with age, highlighting variability within the research construct of functional health literacy. Scoring levels of these tests require psychometric testing for comparison against one another. A common definition of functional health literacy and a comprehensive instrument for its measurement should be agreed upon by researchers so that evidence in the field may become more comparable. In terms of the basic functional health literacy skills required for management of health and well-being in Western systems, the TOFHLA, S-TOFHLA, and potentially the NVS appear to be sensitive to detecting age-related functional limitations. The REALM is less sensitive in detecting age-related limitations in the broad skills required to manage health. The NVS appears promising but remains less tested in terms of its ability to perform well across age groups. Presently, the most appropriate instrument appears to be the TOFHLA or S-TOFHLA due to their relatively common usage, representativeness of daily health-related tasks, and correlation with a range of fluid cognitive abilities.

Longitudinal research that includes adults at age ranges older than 65 years is required to refine our understanding of the dynamics of health literacy decline during aging and its causal processes, cognitive or otherwise. Although direct evidence was limited, existing research suggests that decline in fluid cognitive ability may play a role in aging-related functional health literacy decline. Future research using the TOFHLA, S-TOFHLA, or similar instruments should determine whether the cross-sectional association between age and health literacy holds up in longitudinal studies; the age(s) at which older adults become at risk of health literacy skill loss; the threshold where cognitive aging may begin to affect functional health literacy skills; and the risk and protective factors that predict health literacy skill changes over time among older adults. In the context of these research questions and others, researchers should carefully select which test is most appropriate for their purposes when assessing the functional health literacy skills of older adults.

Supplementary Material

Supplementary material can be found at: http://psychsocgerontology.oxfordjournals.org/

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Appendix 7.2 Complete electronic search strategy

Complete electronic search strategy

Number	Search term	Records returned
1	Middle Aged/ or Adult/ or Aged/ or Age Factors/ or Geriatrics/ or Aging/ or “Aged, 80 and over”/	11590015
2	age*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	16449313
3	aging.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	744764
4	age factors.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	382540
5	adult.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	9475898
6	Risk Factors/	1161722
7	Association/	30271
8	risk factor*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	1581452
9	associat*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	7093802
10	determin*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	5911585
11	predict*.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]	2448616
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	26404641
13	health literacy.mp. or Health Literacy/	8386
14	12 and 13	5867
15	Epidemiologic studies/	154917
16	exp case control studies/	748029
17	exp cohort studies/	1515894
18	Case control.tw.	173575
19	(cohort adj (study or studies)).tw.	199889
20	Cohort analy$.tw.	8822
21	(Follow up adj (study or studies)).tw.	90945
22	(observational adj (study or studies)).tw.	107595
23	Longitudinal.tw.	369286
24	Retrospective.tw.	654285
25	Cross sectional.tw.	397507
26	Cross-sectional studies/	285589
27	Or/15-26	3216843
28	14 and 27	1157
29	Limit 28 to “all adult (19 plus years)” [Limit not valid in Embase, PsycINFO; records were retained]	1076
30	Limit 29 to adulthood <18+ years> [Limit not valid in Embase, Ovid MEDLINE®, Ovid MEDLINE® In-Process; records were retained]	1054
31	Limit 30 to English language	1042
32	Limit 31 to (adult <18 to 64 years> or aged <65+ years>) [Limit not valid in Ovid MEDLINE®, Ovid MEDLINE® In-Process, PsycINFO; records were retained]	873
33	Remove duplicates from 32	502

Appendix 8.1 Published paper in *J Gen Intern Med*

Cognitive Function and Health Literacy Decline in a Cohort of Aging English Adults

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BACKGROUND: Low health literacy is common among aging patients and is a risk factor for morbidity and mortality. We aimed to describe health literacy decline during aging and to investigate the roles of cognitive function and decline in determining health literacy decline.

METHODS: Data were from 5,256 non-cognitively impaired adults aged ≥ 52 years in the English Longitudinal Study of Ageing. Health literacy was assessed using a four-item reading comprehension assessment of a fictitious medicine label, and cognitive function was assessed in a battery administered in-person at baseline (2004–2005) and at follow-up (2010–2011).

RESULTS: Overall, 19.6 % (1,032/5,256) of participants declined in health literacy score over the follow-up. Among adults aged ≥ 80 years at baseline, this proportion was 38.2 % (102/267), compared to 14.8 % (78/526) among adults aged 52–54 years (OR=3.21; 95 % CI: 2.26–4.57). Other sociodemographic predictors of health literacy decline were: male sex (OR=1.20; 95 % CI: 1.04–1.38), non-white ethnicity (OR=2.42; 95 % CI: 1.51–3.89), low educational attainment (OR=1.58; 95 % CI: 1.29–1.95 for no qualifications vs. degree education), and low occupational class (OR=1.67; 95 % CI: 1.39–2.01 for routine vs. managerial occupations). Higher baseline cognitive function scores protected against health literacy decline, while cognitive decline (yes vs. no) predicted decline in health literacy score (OR=1.59; 95 % CI: 1.35–1.87 for memory decline and OR=1.56; 95 % CI: 1.32–1.85 for executive function decline).

CONCLUSIONS: Health literacy decline appeared to increase with age, and was associated with even subtle cognitive decline in older non-impaired adults. Striking social inequalities were evident, whereby men and those from minority and deprived backgrounds were particularly vulnerable to literacy decline. Health practitioners must be able to recognize limited health literacy to ensure that clinical demands match the literacy skills of diverse patients.

KEY WORDS: health literacy; cognition; aging; epidemiology.
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INTRODUCTION

In North America, over half of all adults and over 70 % of adults aged over 65 years have low health literacy, defined as having trouble accessing, understanding, and using information to make basic health decisions.[1,2] Low health literacy is associated with taking of prescription medications improperly, excess use of emergency care, less use of preventive care services, and increased risks for morbidity and mortality.[3–7] Evidently, there is a broad mismatch between individuals' literacy skills and the health management demands placed upon them by health systems, resulting in literacy-based barriers to good health. The improvement of health literacy of populations is a major goal of health organizations including the U.S. Centers for Disease Control and Prevention and the World Health Organization.[8,9]

The health consequences of low literacy may be especially pertinent in older populations, given that older adults commonly need health information and services to manage their increasingly complicated health issues.[10] Cross-sectional research has consistently associated older age with poorer performance on health literacy tests.[11] Subsequently, health literacy skills are assumed to decline during aging. An important consideration for examining the dynamics of health literacy decline in older populations is cognitive aging, as cognitive function is related to health literacy. Fluid cognitive abilities (e.g., working memory, reasoning) and crystallized cognitive abilities (e.g., vocabulary, generalized knowledge) have been shown to jointly explain over 70 % of the association between health literacy and performance on health-related tasks among older adults.[12]

However, the effect of typical cognitive aging processes on health literacy skills remains unclear.[13–19] Furthermore, the distribution of health literacy skill decline in an older population has never been demonstrated, an awareness of which would be imperative for researchers, health practitioners, and policymakers, because low health literacy is a major determinant of morbidity and mortality in the United States, England, and globally.[5,6,20]

Electronic supplementary material *The online version of this article (doi:10.1007/s11606-015-3206-9) contains supplementary material, which is available to authorized users.*

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In this study, we aimed to describe health literacy decline during aging and the potential contributing roles of cognitive function and decline to health literacy decline among non-cognitively impaired English adults aged ≥ 52 years.

METHODS

The English Longitudinal Study of Ageing

The English Longitudinal Study of Ageing (ELSA) is a population-based longitudinal cohort study that aims to characterize the economic, social, and health consequences of aging among English adults aged ≥ 50 years.[21] The original ELSA cohort of 12,100 adults (response rate=66 %) was established in 2002 based on a random stratified sample of households.[21] ELSA data are collected biennially through computer-assisted interviews. The ELSA was approved by the London Multicentre Research Ethics Committee (MREC/01/2/91) and informed consent was obtained from all participants.

Study Sample

All ELSA participants from the original cohort who were in the study at waves 2 (2004–2005) and 5 (2010–2011) of data collection were eligible for inclusion. Wave 2 included 8,780 participants of the original 12,100. Of these, 5,840 were retained at wave 5 (33.5 % attrition between waves 2 and 5) and were eligible for inclusion in the present analysis. Of the 8,780 participants at wave 2, 8,316 (94.7 %) completed the health literacy assessment. Common non-completion reasons were sight difficulties (n=132), health problems (n=59), or that the interview was done by proxy due to physical or cognitive impairment of the participant, and therefore was not eligible for the health literacy assessment (n=92).

Of the 5,840 core participants in the study at wave 5, 5,330 (91.3 %) completed the health literacy assessment. Common reasons for non-completion of the health literacy assessment at wave 5 were sight problems (n=96), health problems (n=37), and having a study interview done by proxy (n=214). In total, 5,256/5,840 participants had data on health literacy at both time points (90.0 %). Of these, one participant was missing data on education, two on ethnicity, and four on occupational class. Cognitive function data were missing for 257 of these participants (4.9 %). The univariate analysis of health literacy decline included all 5,256 participants, the multivariable modelling with sociodemographics included 5,252 participants, and the models including cognitive variables included 4,999 participants.

Health Literacy

Health literacy was assessed using a four-item measure from the Adult Literacy and Life Skills Survey developed by the Organization for Economic Co-operation and Development (OECD) and Statistics Canada.[22] Participants were required to read a fictitious medicine label similar to that found on an aspirin packet, and were asked four reading comprehension questions about the label by the interviewer (Appendix 1). Adequate health literacy was defined as scoring 4/4 correct on the measure and limited health literacy as scoring < 4/4. Health literacy decline was defined as a decrease of ≥ 1 point in score between waves.

Cognitive Variables

Waves 2 and 5 of ELSA collection included an interviewer-administered cognitive battery, which assessed several cognitive processes essential to daily functioning that were sensitive to decline with aging and were measured in a way to prevent ceiling or floor effects.[23] The cognitive processes assessed were: time orientation (ability to state the correct day, week, month, and year), verbal learning (of ten words presented aurally), immediate and delayed recall (of the same ten words), prospective memory (remembering to write initials on a clipboard at a certain point during the battery after being instructed to do so earlier on), verbal fluency and mental flexibility (the number of animals named in one minute), and a test of attention, visual search, and mental processing speed (the number of target letters in a grid of random alphabet letters crossed out in one minute).[23] The former four tests were grouped to create an index of memory function, with potential scores ranging from 0 to 27, and the latter two tests were grouped to create an index of executive function, with potential scores ranging from 0 to no defined upper limit.[23] For each index, cognitive decline was defined as a decline of > 1 point.[23] Memory and executive function collectively will be referred to as 'cognitive function' and collective decline as 'cognitive decline' throughout this paper.

Sociodemographic Covariates

Sociodemographic covariates obtained from the wave 2 interview were: age in years (52–54; 55–59; 60–64; 65–69; 70–74; 75–79; ≥ 80), sex (male; female), ethnicity (white; non-white), educational attainment (degree or equivalent; up to degree level; no qualification), and occupational class according to the three-category UK National Statistics Socioeconomic Classification (managerial; intermediate; routine). Age began at 52 rather than 50 years because this analysis begins 2 years into ELSA data collection. Education was included as a measure of literacy skills gained through schooling, and occupation as a measure of social standing and of literacy skills used throughout working life.

Statistical Analysis

The prevalence of limited health literacy was calculated overall and by 5-year age group at baseline. Mean health literacy scores at each wave were calculated and graphed by 5-year age group, and compared across age groups using the Kruskal-Wallis test and within age groups using the Wilcoxon sign-rank test for matched pairs. Logistic regression models adjusted for all a priori-selected sociodemographic variables were used to estimate odds ratios (ORs) and associated 95 % confidence intervals (CIs) for the associations between age, sociodemographics, and health literacy decline. To prevent baseline adjustment bias,[24,25] baseline health literacy was not adjusted for in regression modelling, as health literacy decline and score at baseline are both strongly correlated with age and likely share other common causes.

Baseline memory and baseline executive function were added to the model to determine their independent associations with health literacy decline and mediating effects on the association with age; memory decline and executive function decline were then added in a second step. A sensitivity analysis was performed, redefining cognitive decline variables according to increasingly conservative definitions of decline: decreases of > 2 and > 5 points on each index. A post-hoc analysis of chronic disease diagnoses that may affect cognition was run to assess their potential additional contribution to explaining the association between age and health literacy. Chronic diseases were diabetes, heart disease (angina, heart attack, abnormal heart rhythm or congestive heart failure), chronic lung disease (chronic bronchitis or emphysema), and depressive symptoms.

The impact of missing data was investigated by running multiple imputations of missing values for health literacy and cognitive function (see full Methods in Appendix 2). All analyses were conducted using StataSE 13.1 (StataCorp, College Station, TX).

RESULTS

At baseline, 1,455/5,256 (27.7 %) participants had limited health literacy (Table 1). When followed forward to wave 5, 3,260/5,256 participants (62.0 %) had no change in their health literacy score, while 964/5,256 (18.3 %) improved by ≥ 1 point and 1,032/5,256 (19.6 %) declined by ≥ 1 point. Chi-squared tests showed that improvement in score was non-differential by age (p=0.53), while decline was more frequent in older age groups (p<0.001). The proportion that declined increased linearly with age from 14.8 % (78/526) of those aged 52–54 years (102/267) to 38.2 % of those aged ≥ 80 years (p<0.0001). As shown in Fig. 1, mean health literacy scores declined over the study follow-up for age groups from 65–69 years and older; this decline was statistically significant for the 75–79 (p=0.008) and ≥ 80 (p<0.001) groups.

In the multivariable logistic regression model adjusted for sex, ethnicity, occupation, and education, the OR for health literacy decline among those aged 65–69 years vs. 52–54 years was 1.34 (95 % CI: 1.00–1.79; Table 2). ORs increased in a linear fashion across age groups (p_{trend}<0.001) up to 3.21 (95 % CI: 2.26–4.57) for the ≥ 80 vs. the 52–54 age group. Independent of baseline age, the sociodemographic risk factors for health literacy decline were: being male (OR=1.20; 95 % CI: 1.04–1.38), of a non-white ethnicity (OR=2.42; 95 % CI: 1.51–3.89), being in an occupational class lower than professional/managerial (OR=1.35; 95 % CI: 1.11–1.65 for intermediate; OR=1.67; 95 % CI: 1.39–2.01 for routine; OR=1.90; 95 % CI: 1.02–3.53 for 'other'), and having no educational qualifications (OR=1.58; 1.29–1.95).

Table 1. Baseline Characteristics of Study Participants, the English Longitudinal Study of Ageing, 2004–2005 (n=5,256)

	N (%)
Age	
52–54	526 (10 %)
55–59	1,346 (26 %)
60–64	995 (19 %)
65–69	952 (18 %)
70–74	692 (13 %)
75–79	478 (9 %)
≥ 80	267 (5 %)
Health literacy	
Limited	1,455 (28 %)
Sex	
Female	2,960 (56 %)
Ethnicity	
Non-white	85 (2 %)
Occupational class	
Managerial	1,797 (34 %)
Intermediate	1,364 (26 %)
Routine	2,040 (39 %)
Other	53 (1 %)
Educational attainment	
Degree or equivalent	1,268 (24 %)
Up to degree level	2,349 (45 %)
No qualification	1,635 (31 %)
Memory index (/27)	
Mean (SD)	16.57 (3.74)
Median	17
Range	4–27
Executive function index	
Mean (SD)	13.66 (3.10)
Median	14
Range	4–23

Mean baseline memory and executive function decreased with age (p<0.0001). Higher baseline cognitive function was protective against health literacy decline regardless of age, where every 1-point increase in memory score was associated with an OR of 0.94 (95 % CI: 0.91–0.96) and every 1-point increase in executive function score was associated with an OR of 0.92 (95 % CI: 0.89–0.94) for health literacy decline (Table 2). The likelihood of cognitive decline over the follow-up period increased with age: 30.9 % (162/525) of those aged 52–54 experienced memory decline, compared with 55.2 % (144/261) of those aged ≥ 80; the corresponding values for executive function decline were 25.6 % (128/500) and 45.3 % (111/245) (p<0.001 for both). As shown in Table 2, memory and executive function decline were associated with health literacy decline independent of age (ORs=1.59; 95 % CI: 1.35–1.87 and 1.56; 95 % CI: 1.32–1.85). Baseline cognitive function and cognitive decline over the follow-up period explained most of the association between health literacy decline and age. The associations between other sociodemographic variables and health literacy decline persisted regardless of adjustment for cognition (Table 2).

When memory decline was defined as declines of > 2 and > 5 points, 1,386/4,999 (27.7 %) and 485/4,999 (9.7 %)

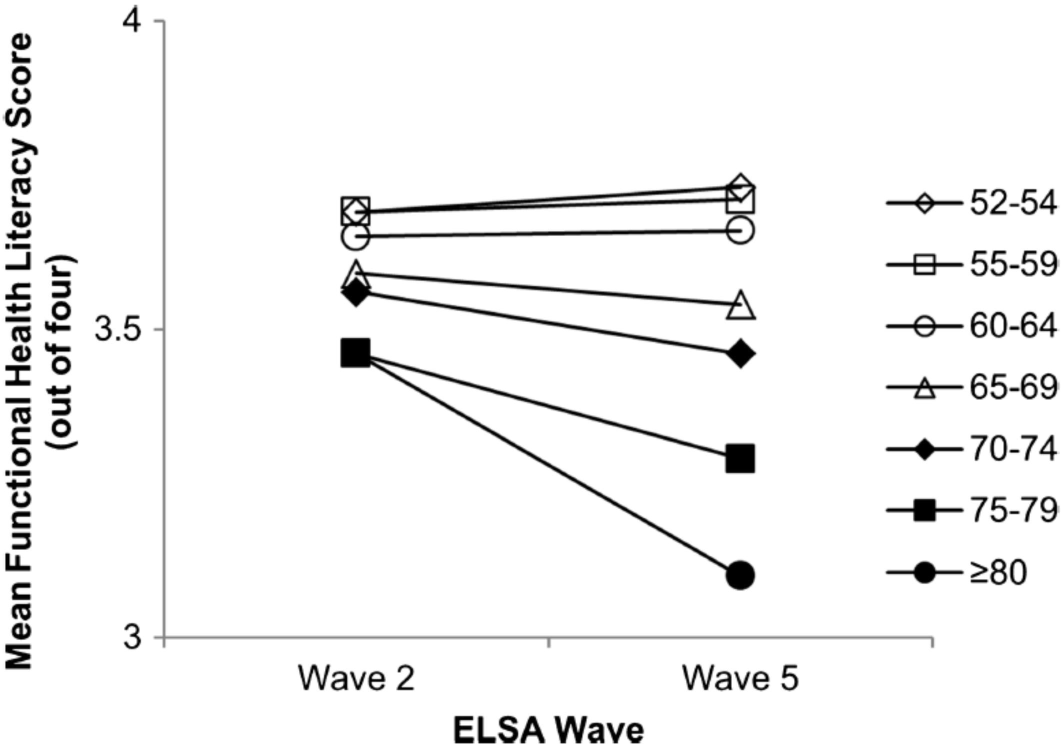

Figure 1. Mean health literacy scores between ELSA waves 2 (2004–2005) and 5 (2010–2011) by 5-year age group.

participants were defined as experiencing memory decline. The corresponding values for these re-definitions of executive function decline were 988/4,999 (19.8 %) and 138/4,999 (2.8 %). When each of these increasingly conservative definitions was used to create the cognitive decline variables, results were unaltered from the original analysis. Having a chronic disease diagnosis or depressive symptoms was not associated with health literacy decline when added to the final model. Finally, results from the multiple imputation analysis were mostly similar to the complete-case analysis (Appendix 2).

DISCUSSION

Nearly one-third of English adults aged 52 years and over had health literacy limitations in this large longitudinal study. Over the 6-year follow-up period, one-fifth of the sample declined in health literacy skills. Age differences in the likelihood and rate of health literacy decline were pronounced, with adults over age 80 having over three times greater odds of experiencing health literacy decline than those in their early 50s. Striking social inequalities in health literacy decline were evident, where men, ethnic minorities, those with no educational qualifications, and those with a lower occupational class were vulnerable to loss of the literacy skills required to manage health during aging. Cognition appears to be a key risk factor explaining health literacy decline. Even subtle, one-point differences in cognitive function affected the likelihood of health literacy decline, and experiencing cognitive decline of any magnitude was strongly associated with health literacy decline.

This study is the first and the largest to our knowledge to track health literacy skills over time, particularly among an aging sample. Our finding that cognitive function mostly explained the relationship between older age and health literacy decline was expected, based on cross-sectional evidence showing that the constructs of cognition and health literacy overlap to a large degree.[12,13,18,26] Contrary to our findings, the association between age and health literacy was independent of cognitive impairment according to the Mini Mental Status Examination (MMSE) score in previous research,[14,16,17] although the MMSE does not detect subtle individual differences in cognitive function. An important aspect of our study is that not everyone who experienced cognitive decline also experienced health literacy decline. The degree to which typical cognitive aging versus aging-

Table 2. Multivariable-Adjusted Associations Between Age, Sociodemographic Factors, Cognition, and Health Literacy Decline, the English Longitudinal Study of Ageing, England, 2004–2011 (n=5256)

	Odds ratios for health literacy decline		
	OR* (95 % CI)	OR† (95 % CI)	OR‡ (95 % CI)
Age			
52–54	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)
55–59	0.92 (0.69–1.23)	0.95 (0.70–1.28)	0.93 (0.68–1.26)
60–64	1.07 (0.80–1.44)	1.04 (0.76–1.41)	0.98 (0.72–1.34)
65–69	1.34 (1.00–1.79)	1.21 (0.90–1.65)	1.08 (0.79–1.48)
70–75	1.53 (1.13–2.07)	1.26 (0.91–1.74)	1.07 (0.77–1.48)
75–79	1.94 (1.41–2.67)	1.43 (1.01–2.03)	1.09 (0.76–1.55)
≥ 80	3.21 (2.26–4.57)	2.26 (1.54–3.32)	1.65 (1.11–2.45)
Sex			
Male	1.20 (1.04–1.38)	1.10 (0.94–1.27)	1.05 (0.90–1.22)
Ethnicity			
Non-white	2.42 (1.51–3.89)	1.81 (1.10–2.99)	1.67 (1.01–2.77)
Occupational class			
Managerial	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)
Intermediate	1.35 (1.11–1.65)	1.26 (1.02–1.55)	1.24 (1.01–1.53)
Routine	1.67 (1.39–2.01)	1.50 (1.23–1.82)	1.43 (1.18–1.74)
Other	1.90 (1.02–3.53)	1.60 (0.83–3.06)	1.44 (0.75–2.77)
Educational attainment			
Degree or equivalent	1.00 (Reference)	1.00 (Reference)	1.00 (Reference)
Up to degree level	1.04 (0.86–1.26)	1.06 (0.87–1.30)	1.07 (0.88–1.31)
No qualification	1.58 (1.29–1.95)	1.33 (1.07–1.66)	1.30 (1.04–1.62)
Baseline memory			
Per 1-point score increase	–	0.96 (0.93–0.98)	0.94 (0.91–0.96)
Baseline executive function			
Per 1-point score increase	–	0.93 (0.91–0.96)	0.92 (0.89–0.94)
Memory decline			
Yes	–	–	1.59 (1.35–1.87)
Executive function decline			
Yes	–	–	1.56 (1.32–1.85)

*Adjusted for covariates (age, sex, ethnicity, occupational class, educational attainment)
†Adjusted for covariates, and baseline memory & executive function; n=4999
‡Adjusted for covariates, baseline memory & executive function, and memory & executive function decline; n=4999*

related cognitive impairments of varying severities affect health literacy skills remains to be elucidated. Our study suggests that non-pathological cognitive decline negatively affects health literacy during aging. Further longitudinal studies that address the fluidity of literacy and cognition during aging are needed for consideration alongside ours.

We observed a degree of health literacy decline among adults aged ≥ 80 years not explained by cognition, which may be because we could not account for all aspects of cognitive function. For example, inductive reasoning was not measured, but is correlated with both age and health literacy.[12,27] Visual and auditory functioning also play roles in one's ability to take in and learn from new information. We did not account for these factors, although participants unable to take the test due to sensory limitations were excluded. We also had no measures of the component processes involved with active learning, including knowledge integration and text inference, which predict reading comprehension skills among older adults.[28] However, the aspects of short-term memory and processing speed that we measured are related to these abilities. It may also be that other factors besides cognitive function influence potential generational differences in likelihood of literacy skill loss, such as lifetime educational experiences.

Although validation data for the individual health literacy measure we used were not available, the measure was taken from a validated international adult literacy survey.[22] The measure does not capture prose literacy, information navigation, or numeracy, although it is a measure of document literacy that has good face validity. The ability to read and understand a medicine label is crucial to several health outcomes, and has been associated with risk of all-cause mortality among older adults.[5] The scale had narrow range and a ceiling effect, where over two-thirds of our study sample scored 4/4 on the scale at both time points; this is a common problem in health literacy measures.[29,30] Consequently, few participants declined by > 1 point (only 316/5,256; 6 %), preventing us from examining decline of varying magnitudes and from varying starting points. We could not examine non-linear change or change longer than our 6-year follow-up period. However, as a longitudinal analysis conducted with little prior knowledge on health literacy during aging, this study provides valuable evidence for future research hypotheses.

Another important limitation of this study is attrition bias. The prevalence of limited health literacy at baseline was 42 % among those who dropped out of the study, but was only 28 % among those who remained in the study between waves. Study attrition also increased with age, from approximately 26 % among those aged 52–54 years to 71 % among those aged ≥ 80 years. Our results may therefore underestimate the true prevalence of limited health literacy among the older English population, particularly in the most elderly age group. Ethnic minorities, participants with no educational qualifications, and those with routine occupations were more also likely to drop out of the study, and were more likely to have limited health literacy at baseline. Therefore, we may have underestimated the magnitude of associations between these sociodemographic variables and health literacy decline. Reassuringly, missing data do not seem to introduce notable bias into our results, as results from the multiple imputation analysis were similar to those from the complete-case analysis.

Future work should investigate more comprehensive aspects of cognition including reasoning and sensory functioning to elucidate the role of cognition in health literacy decline. Longitudinal data should be collected at multiple time points to examine non-linear trajectories of health literacy change over time and for longer follow-up periods than 6 years. Potentially modifiable behavioral and health-related influences on health literacy are unknown. For example, internet use and engagement in regular reading may help adults to maintain health literacy during aging through directly stimulating cognitive and literacy skills. Diagnoses of health conditions, physical functioning, and experiences with the health care system may affect health literacy in multiple complex ways. Future research should investigate these and other potential influences on health literacy decline; if certain practices can help maintain health literacy skills regardless of cognitive aging, this evidence will inform the development of interventions to improve literacy skills in health settings.

CONCLUSIONS

The literacy skills required to manage health appear to undergo aging-related decline among older English adults beginning around age 65. Rate of decline increases with age, with adults aged ≥ 80 years being vulnerable to rapid health literacy decline. Health literacy among older adults is marked by social inequalities, whereby men and adults from deprived social groups are the most vulnerable to skill loss during aging. Cognitive function and even slight cognitive decline during aging appear to affect the likelihood of health literacy decline. Finally, given that literacy skills are commonly lost during aging, a time when adults often need health information and services, the current population-wide burden of low health literacy may be substantial. Innovative interventions to help reduce and prevent literacy barriers to good health during aging are needed, along with individual support from practitioners in daily practice.

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Conflict of Interest: *Michael S Wolf has consulted for Vivus, Abbott, Abbvie, Merck, UnitedHealthcare, and Luto and has received research grants from Abbott, Abbvie, Merck and UnitedHealthcare within the past 3 years, and has been a continuing medical education speaker for MedLearning Group. Lindsay C Kobayashi, Jane Wardle, and Christian von Wagner have no potential conflicts of interest to declare.*

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Appendix 9.1 Published paper in *J Epidemiol Community Health*

Other topics

OPEN ACCESS

Internet use, social engagement and health literacy decline during ageing in a longitudinal cohort of older English adults

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► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/jech-2014-204733).

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ABSTRACT

Background Health literacy skills tend to decline during ageing, which is often attributed to age-related cognitive decline. Whether health literacy skills may be influenced by technological and social factors during ageing is unknown.

Methods We investigated whether internet use and social engagement protect against health literacy decline during ageing, independent of cognitive decline. We used prospective data from 4368 men and women aged ≥52 years in the English Longitudinal Study of Ageing from 2004 to 2011. Health literacy was measured at baseline (2004–2005) and at follow-up (2010–2011) using a reading comprehension test of a fictitious medicine label. The influences of consistent internet use and engagement in each of the civic, leisure and cultural activities on health literacy decline over the follow-up were estimated.

Results After adjusting for cognitive decline and other covariates, consistent internet use (1379/4368; 32%) was protectively associated with health literacy decline (OR=0.77; 95% CI 0.60 to 0.99), as was consistent engagement in cultural activities (1715/4368; 39%; OR=0.73; 95% CI 0.56 to 0.93). As the number of activities engaged in increased, the likelihood of health literacy decline steadily decreased ($p_{trend}<0.0001$), with OR=0.51 (95% CI 0.33 to 0.79) for engaging in all four of the internet use and civic, leisure and cultural activities versus none.

Conclusions Internet use and social engagement, particularly in cultural activities (eg, attending the cinema, art galleries, museums and the theatre), may help older adults to maintain health literacy during ageing. Support for older adults to maintain socially engaged lives and to access the internet should help promote the maintenance of functional literacy skills during ageing.

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INTRODUCTION

Ageing involves rising challenges for health and well-being. During ageing, adults often have increased contact with the healthcare system as risk increases for several chronic diseases and services such as certain types of cancer screening become available. However, age-related cognitive changes and health literacy decline may compromise the ability to navigate the healthcare system and use health information.[1–3] Health literacy is closely related to literacy, and is defined by the Institute of Medicine as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.[4] Among older adults, low health literacy is associated with poor self-care of chronic diseases, excess use of emergency care services, low use of preventive health services and increased risk of overall mortality.[5–8]

A growing body of literature indicates that the most salient explanatory factor in ageing-related health literacy decline is cognitive function.[9–13] In the absence of cognitive impairment, the 'fluid' cognitive abilities that are involved in active learning (eg, working and prospective memory; inductive reasoning) together with 'crystallised' cognitive abilities (eg, vocabulary; generalised knowledge) explain over 70% of the association between health literacy skills and performance on health tasks.[10] Fluid cognitive ability has been shown to decline in a non-pathological manner during ageing beginning in mid-adulthood,[14–16] and also to mostly explain low health literacy among older adults.[17 18] However, the influences of technological and social factors that involve active learning and cognitive stimulation on health literacy during ageing have never been investigated in a longitudinal manner.

Cross-sectional research has found that adults with lower health literacy are less likely to use the internet than those with adequate health literacy.[19 20] Furthermore, a randomised online eHealth intervention focused around the learning of new health information has been shown to improve the performance of adults diverse by age and culture on health literacy assessments.[21] Internet use has also been longitudinally associated with the maintenance of cognitive function during ageing.[22–24] Randomised evidence shows that trained use of tablet computers, involving use of the internet in practical applications, improves executive function over social and non-intellectually stimulating activities among older American adults.[25]

With respect to social engagement, a body of longitudinal research with long-term follow-up shows that a diverse range of social activities including physical activity, intellectual game-playing, membership in religious and other social groups and participation in cultural activities all protect against several measures of cognitive decline during ageing.[26–31] However, in a shorter 3-month randomised trial of socially and cognitively stimulating activities, cognitive function was not improved in a social engagement group of older adults (activities such as field trips that were novel but did not involve active learning), whereas it was in a 'receptive engagement' group (active learning of novel skills).[32] Evidently, this body of knowledge is still evolving, although it appears that cognitively-stimulating social activities may help maintain cognitive function during ageing. This relationship may extend to health literacy.

We hypothesise that internet use and engagement in intellectually-stimulating social activities may have positive effects on the maintenance of health literacy skills during ageing. The objective of this study is to investigate the roles of internet use and social engagement (in civic, leisure and cultural activities) in health literacy decline during ageing among a population-based sample of English adults aged ≥52 years in the English Longitudinal Study of Ageing (ELSA).

METHODS

English Longitudinal Study of Ageing

ELSA is a longitudinal cohort study representative of the English population aged ≥50 years, established in 2002 as a stratified random sample of a private household.[33] Data are collected biennially through computer-assisted in-person interviews and nurse-conducted health assessments are performed every 4 years. ELSA was approved by the London Multicentre Research Ethics Committee (MREC/01/2/91) and informed consent was obtained from all participants. The present analysis uses data from ELSA participants aged ≥52 years in waves 2 (2004–2005), 3 (2006–2007), 4 (2008–2009) and 5 (2010–2011) of the ELSA data collection. Eligible participants were 'core' ELSA members recruited in the original data collection wave (2002–2003), who participated in all data collection waves with non-proxy interviews (n=5133).

Study measures

Health literacy

Health literacy was measured at waves 2 (baseline) and 5 (follow-up) of ELSA during the in-person study interview. Participants were shown a fictitious medicine label similar to that found on a bottle of aspirin and asked four reading comprehension questions by the interviewer (see online supplementary material 1). The measure was developed by the Organisation for Economic Co-operation and Development (OECD) and Statistics Canada for the Adult Literacy & Life Skills Survey[34] to reflect the goal-based, clinically-relevant health task of understanding and interpreting instructions on a medicine label. Health literacy decline was defined as decreasing in score by ≥1 point between waves 2 and 5.[6]

Internet use

Data on internet use were collected in a self-completion questionnaire that ELSA participants completed in addition to the in-person interview. Internet use was assessed at each wave using a checklist item, 'I use the internet and/or email'. 'Never users' were those who did not tick the item in any wave, 'Intermittent users' inconsistently ticked the item across waves 2–5, and 'Consistent users' ticked the item in all waves.

Social engagement

Social engagement is conceptualised in this analysis using an index of 'social detachment' from ELSA.[33] The index includes a range of civic, leisure and cultural activities that would use diverse cognitive abilities including those involved in active learning (table 1). A crude social network measure (ie, having friends, children or other immediate family and being in contact with them at least once per week) was included in the index but not used in the present study, due to the low variability in response to the variable and a lack of empirical evidence for the

Table 1 Civic, leisure and cultural activities classified in the English Longitudinal Study of Ageing

Civic activities	Current member of a ▶ political party; ▶ trade union or environmental group; ▶ tenants' or neighbourhood group or neighbourhood watch; ▶ church or religious group; ▶ charitable association; And did volunteer work in the past year
Leisure activities	Current membership in a ▶ social club; ▶ sports club; ▶ gym or exercise class; ▶ other organisation, club or society
Cultural activities	In the past year, attending a ▶ cinema; ▶ art gallery or museum; ▶ theatre, concert or opera performance

association between this variable and cognitive stimulation. Data were collected in the self-completion questionnaire, where participants ticked off the statements relating to them in each wave. Participants were categorised as being engaged or not engaged in each domain at each wave. Across waves, social engagement was described as being 'Consistent', Intermittent' or 'None' for each domain.

Covariates

Sociodemographic and health-related covariates considered as potential confounders were: age at wave 2 of the data collection, sex, ethnicity (white; non-white), educational attainment (degree or equivalent; up to degree level; no qualification), net non-pension wealth quintile (stratified at age 65 to account for retirement), having a limiting long-standing illness (yes; no), and experiencing a limitation in any instrumental activity of daily living (IADL) over the follow-up period (yes; no). Cognitive covariates were: baseline memory (score out of 27 on the memory index, consisting of time orientation, immediate and delayed recall, and prospective memory), baseline executive function (score out of infinity on the executive function index, consisting of verbal fluency and mental processing speed), memory decline, and executive function decline (yes or no for a decline of >1 point on the index for each wave between waves 2 and 5).[35]

Study sample

At wave 2, 5024/5133 (97.9%) eligible participants completed the health literacy assessment. Reasons for non-completion of the health literacy assessment were sight problems (n=35), health problems (n=9) and refusals without a reason or a non-codeable reason given (n=65). At wave 5, 4853/5133 (94.5%) eligible participants completed the health literacy assessment and therefore had a follow-up health literacy measure. Reasons for non-completion at wave 5 were: sight difficulties (n=85), health problems (n=33), reading problems (n=25), other problems such as anxiety, illness or other mental impairment (n=29), or refusal without a reason given (n=77). Overall, 4837/5133 (94.2%) participants had complete health literacy data, 4710/5133 (91.8%) had complete cognitive function data and 4859/5133 (94.7%) had net non-pension wealth data. When all missing data were accounted for, the final sample size was 4368. The effective sample size for the multivariable-adjusted models was 4365, as two participants were missing data on ethnicity and one on education.

Statistical analysis

Sample characteristics were analysed bivariately against health literacy decline using the χ^2 test for categorical variables and Student's t test for continuous variables. The proportions of internet users and those engaged in each social domain were calculated for each data collection wave. Multivariable logistic regression was used to estimate ORs and 95% CIs for the associations between internet use and engagement in each of the civic, leisure and cultural activities (four main effects) and health literacy decline over the 6-year follow-up. Three model sets were run: model set 1 was for the associations between each main effect and health literacy decline, adjusted for sociodemographic and health-related covariates; model 2 adjusted for all main effects simultaneously in addition to covariates; model 3 additionally included baseline cognitive function and cognitive decline variables. A secondary analysis investigated the additive effect of maintaining engagement in one, two, three or all four of the internet use and civic, leisure and cultural activities over the follow-up. To avoid the baseline adjustment bias, baseline health literacy was not adjusted for.[36] We ran a multiple imputation analysis to account for missing health literacy and cognitive function data (see online supplementary material 2). All analyses were conducted using StataSE V.13.1 (StataCorp, College Station, Texas, USA).

RESULTS

At baseline, 3187/4368 participants (73%) had adequate health literacy (table 2). Over the 6-year follow-up, 814/4368 participants (19%) declined by one or more point in the health literacy score, while 791/4368 (18%) improved by one or more points. The proportion of adults who declined in the health literacy score increased with age ($p<0.0001$), while improvement was non-differential by age ($p=0.42$). Being older, non-white, in a lower wealth quintile, having no educational qualifications, and experiencing at least one IADL limitation over the follow-up were associated with health literacy decline (table 2). Lower memory and executive function scores at baseline were associated with health literacy decline, as was experiencing cognitive decline over the follow-up (table 2).

Across the data collection waves, 1755/4368 participants (40%) reported never using the internet or email and 1234/4368 (32%) consistently reported their use. Across waves, 1539/4368 participants (35%) were consistently engaged in civic activities, 1373/4368 (31%) in leisure activities and 1715/4368 (39%) in cultural activities. Participation across civic, leisure and cultural activities was significantly but modestly correlated with Spearman's r, ranging from 0.31 to 0.37 ($p<0.0001$ for all). Among those who experienced health literacy decline, internet use and engagement in all three social domains were lower at each wave than in those who did not decline ($p<0.0001$ for all waves).

In logistic regression adjusted for sociodemographic and health-related covariates, consistent internet use was protectively associated with health literacy decline (OR=0.60; 95% CI 0.49 to 0.76 vs never use), as was consistent engagement in civic and cultural activities (table 3). When all four main effects were mutually adjusted for in the same model, the association with civic activities was attenuated to the null. When cognitive variables were entered into the model, the associations with internet use and cultural engagement were somewhat attenuated, but remained statistically significant. The OR for consistently engaging in any one of the internet use, civic, leisure or cultural activities versus no engagement was 0.93 (95% CI 0.76 to 1.14), compared to 0.81 (95% CI 0.63 to 1.02) for engaging in any two activities, 0.70 (95% CI 0.53 to 0.94) for engaging in any three activities, and 0.51 (95% CI 0.33 to 0.79) for engaging in all four activities, a significant linear trend in effects ($p_{trend}<0.0001$; table 4).

The multiple imputation analysis yielded similar results to the complete-case analysis (see online supplementary material 2).

Table 2 Characteristics of study participants by health literacy decline, the English Longitudinal Study of Ageing, 2004–2011 (n=4368)

	Health literacy decline		
	Yes (n=814; 19%)	No (n=3554; 81%)	p Value
Age			<0.0001
Mean (SD)	66.97 (8.99)	64.03 (8.09)	
Sex			0.37
Male	369 (19%)	1549 (81%)	
Female	445 (18%)	2005 (82%)	
Ethnicity			0.02
White	797 (18%)	3513 (82%)	
Non-white	17 (30%)	39 (70%)	
Educational attainment			<0.0001
Degree or equivalent	149 (14%)	925 (86%)	
Up to degree level	330 (17%)	1656 (83%)	
No qualification	334 (26%)	973 (74%)	
Non non-pension wealth quintile			<0.0001
1 (poorest)	155 (24%)	501 (76%)	
2	154 (19%)	653 (81%)	
3	180 (20%)	703 (80%)	
4	155 (16%)	808 (84%)	
5 (richest)	170 (16%)	889 (84%)	
Limiting long-standing illness			0.17
No	366 (18%)	1692 (82%)	
Yes	448 (19%)	1862 (81%)	
IADL limitation over study follow-up			<0.0001
No	542 (17%)	2649 (83%)	
Yes	272 (23%)	905 (77%)	
Baseline health literacy			<0.0001
Adequate	656 (21%)	2531 (79%)	
Limited	158 (13%)	1023 (87%)	
Baseline memory (range: 4–27)			<0.0001
Mean (SD)	15.45 (3.83)	16.93 (3.62)	
Baseline executive function (range: 5–23)			<0.0001
Mean (SD)	12.80 (3.12)	13.92 (3.04)	
Memory decline			<0.0001
No	488 (17%)	2429 (83%)	
Yes	379 (22%)	1313 (78%)	
Executive function decline			<0.0001
No	521 (17%)	2616 (83%)	
Yes	346 (24%)	1126 (76%)	

IADL, instrumental activity of daily living.

DISCUSSION

In this longitudinal cohort of English adults aged 52 years and above, consistent internet use and engagement in cultural activities including attending the theatre, cinema, art galleries,

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Table 3 Associations between internet use, social engagement and health literacy decline, the English Longitudinal Study of Ageing, 2004–2011 (n=4368)

	Health literacy decline							
Activities	Yes (n=814; 19%)	No (n=3554; 81%)	Model 1*	95% CI	Model 2†	95% CI	Model 3‡	95% CI
Internet use								
Never	435 (25%)	1320 (75%)	1.00		1.00		1.00	
Intermittent	218 (18%)	1016 (82%)	0.85	(0.69 to 1.03)	0.86	(0.70 to 1.05)	0.92	(0.75 to 1.13)
Consistent	161 (12%)	1218 (88%)	0.60	(0.49 to 0.76)	0.68	(0.54 to 0.87)	0.77	(0.60 to 0.99)
Civic activities								
None	263 (23%)	876 (77%)	1.00		1.00		1.00	
Intermittent	317 (19%)	1373 (81%)	0.83	(0.69 to 1.01)	0.87	(0.71 to 1.05)	0.85	(0.70 to 1.04)
Consistent	234 (15%)	1305 (85%)	0.72	(0.58 to 0.89)	0.82	(0.65 to 1.02)	0.84	(0.67 to 1.06)
Leisure activities								
None	246 (21%)	905 (79%)	1.00		1.00		1.00	
Intermittent	360 (20%)	1484 (80%)	1.05	(0.87 to 1.27)	1.14	(0.94 to 1.39)	1.18	(0.97 to 1.44)
Consistent	208 (15%)	1165 (85%)	0.85	(0.68 to 1.06)	1.05	(0.83 to 1.33)	1.12	(0.88 to 1.42)
Cultural activities								
None	227 (26%)	637 (74%)	1.00		1.00		1.00	
Intermittent	368 (21%)	1421 (79%)	0.88	(0.72 to 1.07)	0.90	(0.73 to 1.10)	0.92	(0.75 to 1.14)
Consistent	219 (13%)	1496 (87%)	0.60	(0.47 to 0.75)	0.67	(0.53 to 0.87)	0.73	(0.56 to 0.93)

*Adjusted for age, sex, ethnicity, educational attainment, net non-pension wealth, having a limiting long-standing illness, experiencing an IADL limitation.
†Model 1+internet use and engagement in each of the civic, leisure and cultural activities.
‡Model 2+baseline executive function, baseline memory, executive function decline and memory decline.
IADL, instrumental activity of daily living.

museums, concerts or opera at least once a year were individually associated with ageing-related health literacy decline in a protective manner. As the number of activities engaged in increased, the protective association with health literacy decline increased in magnitude. When all four of the internet use, civic, leisure and cultural activities were consistently engaged in, the protective association was the strongest. These relationships were independent of cognitive function and decline.

Strengths and weaknesses of this study

Our health literacy measure was developed, validated, and used by the OECD for an international adult literacy survey.[34] Although individual validation metrics were unavailable for the measure, performance on it is associated with participation in cancer screening[6] and all-cause mortality,[7] showing its predictive capability for health outcomes. A limitation is that the clinically relevant task of understanding a medicine label is not representative of the diverse situations in which health literacy applies. The health literacy field is plagued by this problem, whereby objective instruments that comprehensively measure health literacy according to its multiple and sometimes conflicting definitions are not yet developed.[37]

Our four-point scale displayed a ceiling effect common to measures of health literacy.[38 39] The narrow scale range also resulted in few participants declining by more than one point over the follow-up: of those who declined (814/4368), 585 declined by one point, 170 by two points, 50 by three points, and 9 by four points. Owing to these small numbers, we could not discriminate between these magnitudes of decline as outcomes. Similar yet more comprehensive instruments also use health artefacts,[38] but are less practical for incorporation in long, interview-based studies like ELSA. Improvement in the health literacy score over time was non-differential by age, indicating that decline is an age-related phenomenon and not due to random response error.

As with any population-based study, two main limitations are non-response bias and attrition bias. Older, non-white and less-educationally qualified adults were under-represented in wave 2 of ELSA (81.5% response rate) and were more also likely to drop out of the study between waves 2 and 5 (42% overall attrition rate among core members). These demographic factors were significantly associated with internet use, social engagement and health literacy decline. Therefore, we may have underestimated the magnitudes of the protective associations that we observed due to differential attrition. Our chance of a type I error may be inflated due to the multiple associations we tested. Missing data are unlikely to bias the results of this study, as the results were negligibly altered in the multiple imputation analysis.

Cognitive function was assessed in the face-to-face study interview using multiple validated measures of memory and executive function.[36] However, we had no measure of

Table 4 The additive effects of internet use and social engagement on health literacy decline, the English Longitudinal Study of Ageing, 2004–2011 (n=4368)

	OR*	95% CI
Per additional activity	0.87	(0.81 to 0.94)
Number of activities engaged in†		
None	1.00	
One	0.93	(0.76 to 1.14)
Two	0.81	(0.63 to 1.02)
Three	0.70	(0.53 to 0.94)
Four	0.51	(0.33 to 0.79)

*Adjusted for age, sex, ethnicity, educational attainment, net non-pension wealth, having a limiting long-standing illness, experiencing an IADL limitation, baseline executive function, baseline memory, executive function decline and memory decline.
†The four activities referred to are internet use and each of civic, leisure, and cultural activities.
IADL, instrumental activity of daily living.

reasoning, which is a predictor of health literacy.[10] Therefore, our cognitive indices may have been less strongly associated with health literacy than those including reasoning. We were also unable to measure specific activities within each domain of social engagement (eg, specific types of volunteer work, educational classes and theatre shows). The cognitive demands of specific activities would vary, which could have caused a non-differential misclassification biasing of our results to the null. This important lack of information and the potential for reverse causality due to our longitudinal, but not necessarily causal, models limit the extent to which we and others can make hypotheses about the specific cognitive learning processes through which health literacy may be improved. However, our findings open several areas of inquiry regarding the mechanisms through which internet use and social engagement may influence health literacy skills.

Comparison with other studies

The longitudinal relationships between internet use, social engagement and health literacy have never been investigated to the best of our knowledge, particularly never among an ageing sample. Our hypothesis regarding internet use and health literacy decline was supported, consistent with two previous cross-sectional studies.[19 20] It appears from our study that the relationship between internet use and health literacy decline is only partly explained by memory and executive function. Although we could not investigate these pathways, internet use may also promote health literacy skills through:

A. Providing opportunities for health knowledge acquisition;
B. Improving other cognitive functions such as reasoning;
C. Providing social benefits through social media and networking sites;
D. Training the specific navigational and digital skills required to use the internet.

Our hypothesis that intellectually-stimulating social engagement would be protective against health literacy decline was mostly supported. It may be that the categories in the leisure activity domain were too general to observe an association, and/or that they involved passive engagement, which has no effect on cognitive function.[32] With respect to cultural activities, these would most likely engage several fluid cognitive abilities depending on the specific show or exhibit. Importantly, the association we observed was independent of wealth, education, having a limiting long-standing illness or experiencing IADL limitations over the follow-up, indicating that cultural engagement is not a proxy for socioeconomic circumstances or good physical capability.

Although additional studies with more comprehensive cognitive function measures are needed, we found that internet use and social engagement were associated with health literacy independently of memory and executive function measures. However, health literacy has recently been postulated to be little more than a marker of cognitive function.[11 40] Our findings suggest that even if this were the case, it would be premature to assume an overly deterministic view of health literacy. Ignoring health literacy, and by extension all literacy, as an innate or predetermined ability would be a disservice to all those who experience literacy-based barriers to health and well-being in society. This paper highlights the usefulness of putting health literacy in the context of both cognitive and social functions, particularly when trying to better understand changes to health literacy skills in later life.

CONCLUSION

Our results indicate that internet use and social engagement may help older adults to maintain the functional literacy skills required to manage health. Individually, internet use and cultural engagement appeared to have beneficial associations. Together, all four factors appeared to act in an additive fashion, with the more the better for maintaining literacy skills. Further studies with additional cognitive, technological and social measures are needed for consideration alongside ours. The socially-embedded and intersecting problems of low internet use, low social engagement and health literacy decline are complex and will most likely require multimodal interventions to overcome. As an early longitudinal investigation in this area, our study should bring about several new hypotheses about the social and cognitive processes that influence the dynamics of literacy at older ages, and how they may be modified.

What is already known on this subject

Cross-sectional research consistently shows an association between older age and low health literacy, which is often attributed to cognitive ageing. There is no longitudinal evidence for modifiable technological or social influences on health literacy skills during ageing.

What this study adds

Internet use and engagement in various social activities, in particular cultural activities, appear to help older adults maintain the literacy skills required to self-manage health. These factors appeared to act in an additive fashion, with the more the better for maintaining literacy skills. Results indicate that health literacy skills are fluid over time, that loss of literacy skills during ageing is not inevitable, and that technological and social factors should be understood as influences on literacy skills.

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Contributors LCK and CvW devised the research question. LCK conducted the statistical analysis and drafted the manuscript. All authors contributed to the interpretation of data, critical revisions to the manuscript for important intellectual content, and have approved the final version to be published. All authors had full access to the study data and agree to be accountable for all aspects of the work.

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Competing interests None.

Ethics approval The English Longitudinal Study of Ageing was approved by the London Multicentre Research Ethics Committee (MREC/01/2/91) and informed consent was obtained from all participants.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Users registered with the Economic and Social Data Service (ESDS) have access to the English Longitudinal Study of Ageing data sets, available at http://www.esds.ac.uk.

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Appendix 10.1 Published paper in *Prev Med*

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Limited health literacy is a barrier to colorectal cancer screening in England: Evidence from the English Longitudinal Study of Ageing☆

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ABSTRACT

Objective. To determine the association between health literacy and participation in publicly available colorectal cancer (CRC) screening in England using data from the English Longitudinal Study of Ageing (ELSA).

Methods. ELSA is a population-based study of English adults aged ≥50 years. Health literacy, participation in the national CRC screening programme, and covariates were interview-assessed in 2010–11. All those age-eligible for screening from 2006 to 11 were included in the present analysis (n = 3087). The association between health literacy and screening was estimated using multivariable-adjusted logistic regression.

Results. 73% of participants had adequate health literacy skills. Screening uptake was 58% among those with adequate and 48% among those with limited health literacy skills. Having adequate health literacy was associated with greater odds of CRC screening (multivariable adjusted OR = 1.20; 95% CI: 1.00–1.44), independent of other predictors of screening: age (OR = 0.92; 95% CI: 0.91–0.94 per one year increase), female sex (OR = 1.31; 95% CI: 1.11–1.54), and being in a higher wealth quintile (OR = 1.88; 95% CI: 1.43–2.49).

Conclusions. Limited health literacy is a barrier to participation in England's national, publicly available CRC screening programme. Interventions should include appropriate design of information materials, provision of alternative support, and increased one-on-one interaction with health care professionals.

Introduction

Colorectal cancer (CRC) is a leading cause of global cancer burden among men and women (Ferlay et al., 2010). In the United Kingdom (UK), CRC is the third most common incident cancer and cause of cancer death, with over 40,000 new cases and over 15,000 deaths in 2010 (Cancer Research UK, 2013). England is one of the first countries worldwide to implement a national, organised, publicly available screening programme using the faecal occult blood test (FOBT). The screening programme, entitled the National Bowel Cancer Screening Programme, is operated through the National Health Service (NHS) and was fully implemented in 2010. All adults aged 60–69 (currently being extended to 74) are eligible and receive a written screening invitation through the post with screening information and the home-based FOBT kit biennially beginning in the year of the 60th or 61st birthday.

Although the FOBT reduces mortality (Hewitson et al., 2008; Mandel et al., 1993), overall uptake of screening in England is low and substantially socially graded. An analysis of the first 2.6 million invitations to the programme from 2006 to 09 found that overall uptake was 54%, but was substantially lower among men and among adults living in deprived and ethnically diverse neighbourhoods (von Wagner et al., 2011). A further source of inequality in CRC screening participation in England may be low health literacy. Health literacy is defined as an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine, 2004). Limited health literacy is associated with increased use of emergency care services, elevated risks for several chronic diseases and overall mortality, and poorer use of preventive health services such as cancer screening (Baker et al., 1998; Bennett et al., 2009; Berkman et al., 2011; Bostock and Steptoe, 2012). Health literacy has inconsistently been associated with CRC screening in three American studies (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007), although higher health literacy has been associated with increased knowledge and positive attitudes toward the benefits of screening (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007).

In England's Bowel Cancer Screening Programme, the primary mode of communication with eligible adults is through written screening information materials mailed through the post. Therefore, limited health literacy skills may in part explain the overall low uptake of screening and social inequalities in screening: they may inhibit some individuals' capacity to understand, and subsequently engage with the written screening information (Davis et al., 2001; Dolan et al., 2004; von

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Wagner et al., 2009a). Health literacy has not yet been investigated with respect to its role in participation in CRC screening when made publicly available, as in England.

Using data from the population-based English Longitudinal Study of Ageing (ELSA), we aimed to determine: 1) the prevalence and predictors of limited health literacy in an English population eligible for CRC screening, 2) the association between health literacy and participation in the FOBT-based NHS Bowel Cancer Screening Programme in England.

Methods

Study sample

The ELSA is a longitudinal cohort study of the English population aged ≥50 years (Taylor et al., 2007). Data are collected biennially through computer-assisted interviews. The 'core' ELSA study population consists of participants from the original sample established in 2002 and newer participants added at each wave of data collection to account for ageing of the original sample. Male and female core ELSA participants aged 60–75 at wave 5 (2010–11) who completed the health literacy assessment and the CRC screening questions were eligible for the present analysis. This age group covers those eligible for FOBT screening with the NHS Bowel Cancer Screening Programme at any point from its inception in 2006 to the time of data collection in 2010–11.

In total, 8741 core participants with non-proxy interviews completed data collection at wave 5. Of these, 5041 (58%) were aged 60–75 years. Due to field-work logistics, the interview questions about cancer screening were introduced partway through data collection and subsequently screening data are not complete for the entire sample. Of the 5041 eligible participants, 3087 (61%) were asked the cancer screening questions. Of these, 2995 (97%) completed the health literacy assessment. Refusals were due to: reading problems (n = 14), sight difficulties (n = 14), health problems (n = 15), other reasons including anxiety, impaired concentration, distress, etc. (n = 15), or an unknown reason (n = 34). Refusals were included and coded as limited health literacy, as these people are likely to perform with limited health literacy skills in real-life settings (e.g. at the doctor's office) because of their difficulties. Therefore, they were included to maintain the population-representativeness of the sample and capture a more accurate range of the health literacy skills of the English population. The present analysis thus included 3087 men and women aged 60–75 years (Fig. 1).

Health literacy assessment

Health literacy was assessed using a four-item comprehension test based on a fictitious medicine label from the International Adult Literacy Survey (Thorn, 2009) (Appendix A). Health literacy was categorised as 'adequate' (4/4 questions answered correctly) or 'limited' (<4/4 answered correctly) to capture the point at which adults begin to have difficulty with everyday health tasks. Although whether and how health literacy skills may change over time are uncertain, health literacy scores among our sample are expected to be stable between data collection and the times of reported CRC screenings (within one year of

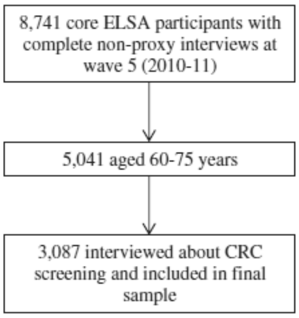

Fig. 1. Inclusion flow diagram, the English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

wave 5 data collection for 59% of those reporting screening and within two years for 96%). Health literacy was also measured at ELSA wave 2 (2004–5) and the scores did not change between waves 2 and 5 within individuals who remained in the study for both waves. Health literacy scores measured at wave 2 were not used for this analysis, as study attrition between waves was differential by health literacy score.

Colorectal cancer screening

Participants were asked if they had ever used a bowel testing kit (i.e. an FOBT kit) and whether the kit was part of the NHS Bowel Cancer Screening Programme. Only 49 out of the 1709 participants (<3%) who reported having completed an FOBT kit responded that the kit was not part of the NHS programme and 3 (<1%) responded that they did not know whether it was part of the programme; hence for this analysis we assume that completion of a FOBT kit equates with participation in the NHS programme. For convenience, the terms "completion of an FOBT kit" and "CRC screening" will hereupon be used synonymously.

Covariates

Sociodemographic covariates were: age, sex (male; female); educational attainment (no qualification; up to degree level; degree level or equivalent); net non-pension wealth (quintiles stratified at age 65 to account for changes in wealth following retirement) (Bostock and Steptoe, 2012); occupational class according to the 2010 National Statistics Socio-economic Classification (routine; intermediate; managerial or professional) (Office for National Statistics, 2010); and ethnic minority status (non-white; white).

Health-related covariates were: having a limiting long-standing illness (yes; no); having limitations in any one of six activities of daily living: dressing, walking across a room, bathing or showering, eating, getting in and out of bed, using the toilet (yes; no) (Bostock and Steptoe, 2012); having difficulty using the toilet including getting up and down (yes; no; this activity of daily living was also considered separately due to its specificity to completing an FOBT kit); having depressive symptoms, classified as scoring more than four on the eight-item Centre for Epidemiologic Studies depression scale (yes; no) (Radloff, 1977); self-reported general health (fair/poor; excellent/very good/good); and having ever been diagnosed with cancer (yes; no).

Statistical analysis

To achieve objective 1), the prevalence of adequate and limited health literacy were calculated. Unadjusted logistic regression modelling was used to generate odds ratios (ORs) and associated 95% confidence intervals (CIs) for the associations between health literacy and all covariates. Linear trend tests were used to assess graded relationships between ordered variables and health literacy. The same analyses were then conducted between participation in CRC screening and all covariates.

To achieve objective 2), the independent association between having adequate health literacy and participation in CRC screening was estimated using multivariable-adjusted logistic regression. Age, sex, educational attainment, and net non-pension wealth were forced into the model and all health-related covariates associated with screening with $p < 0.20$ in bivariate analysis were included in the initial model and retained if their deletion resulted in a ≥10% change in the OR for the association between health literacy and CRC screening (Rothman and Greenland, 1998).

Two sensitivity analyses were conducted. The first excluded those who refused to complete the health literacy assessment (n = 92) to ensure that these participants were not misclassified in a way to cause bias. The second excluded those who reported completing FOBT-based CRC screening outside of the national programme (n = 49). All regression modelling was performed with population weights applied to account for differential non-response across population subgroups (NatCen Social Research, 2012). All statistical tests were two-sided and performed at the 95% confidence level. All statistical analyses were conducted using StataSE 12.0 (StataCorp, College Station, TX).

Results

Nearly one in three ELSA participants eligible for CRC screening lacked adequate health literacy skills (Table 1). Health literacy was non-differential by gender, while those with higher educational

Table 1
Unadjusted associations between health literacy and covariates, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Health literacy level				
	Adequate (n = 2264; 73%)	Limited (n = 823; 27%)	Unadjusted OR for adequate health literacy	95% CI	p-Value
Age (mean (SD))	66.3 (4.5)	67.5 (4.7)	0.94[a]	(0.92, 0.96)	<0.0001
Sex					
Male	1010 (72%)	385 (28%)	1.00		
Female	1254 (74%)	438 (26%)	1.13	(0.95, 1.33)	0.17
Educational attainment					
No qualification	416 (57%)	319 (43%)	1.00		<0.0001[b]
Up to degree level	1168 (77%)	340 (23%)	2.78	(2.28, 3.38)	
Degree or equivalent	680 (81%)	164 (19%)	2.97	(2.34, 3.77)	
Occupational class					
Routine	769 (64%)	436 (36%)	1.00		<0.0001[b]
Intermediate	624 (76%)	201 (24%)	1.83	(1.49, 2.25)	
Managerial	859 (83%)	176 (17%)	3.00	(2.44, 3.69)	
Net non-pension wealth fifth					
1 (poorest)	309 (64%)	176 (36%)	1.00		<0.0001[b]
2	396 (70%)	172 (30%)	1.32	(1.01, 1.72)	
3	430 (76%)	133 (24%)	1.74	(1.31, 2.31)	
4	486 (75%)	159 (25%)	1.71	(1.30, 2.23)	
5 (richest)	532 (82%)	115 (18%)	2.77	(2.07, 3.69)	
Ethnicity					
Non-white	33 (43%)	44 (57%)	1.00		<0.0001
White	2231 (74%)	779 (26%)	3.33	(2.01, 5.53)	
Limiting longstanding illness					
Yes	656 (66%)	340 (34%)	1.00		<0.0001
No	1608 (77%)	483 (23%)	1.81	(1.52, 2.15)	
Limited activities of daily living					
Yes	279 (61%)	182 (39%)	1.00		<0.0001
No	1985 (76%)	641 (24%)	2.05	(1.65, 2.55)	
Difficulty using the toilet					
Yes	42 (55%)	34 (45%)	1.00		0.001
No	2222 (74%)	789 (26%)	2.21	(1.37, 3.56)	
Depressive symptoms					
Yes	161 (64%)	91 (36%)	1.00		<0.0001
No	2087 (75%)	709 (25%)	1.71	(1.28, 2.27)	
Self-reported general health					
Fair/poor	438 (59%)	303 (41%)	1.00		<0.0001
Excellent/very good/good	1826 (78%)	519 (22%)	2.47	(2.05, 2.97)	
Ever been diagnosed with cancer					
Yes	151 (73%)	56 (27%)	1.00		0.67
No	2113 (73%)	767 (27%)	1.08	(0.77, 1.51)	

[a] Per one year increase in age.
[b] p-Value for linear trend.

qualifications, of an intermediate or managerial occupational class, of any wealth quintile above the poorest, and of a white ethnicity were more likely to have adequate health literacy skills (Table 1). Not having a limiting long-standing illness, any limitations in activities of daily living, or depressive symptoms and having excellent, very good, or good general health were associated with having adequate health literacy skills. Having a previous cancer diagnosis was not associated with health literacy.

The overall participation rate in FOBT-based CRC screening was 55% (Table 2). Participation rates were 58% among those with adequate health literacy and 48% among those with limited health literacy (Table 2). In the unadjusted model, having adequate health literacy was associated with 50% greater odds of participating in CRC screening (OR = 1.50; 95% CI: 1.27–1.78). Other positive predictors of CRC screening participation in unadjusted models were female sex, having up to degree or degree level educational qualifications, being of managerial occupational class, being in any wealth quintile above the poorest, not having a limiting long-standing illness, limited activities of daily living, or depressive symptoms, and having excellent, very good, or good self-rated health. Older age was associated with being less likely to screen.

When adjusted for age, sex, educational attainment, and net non-pension wealth, the association between adequate health literacy and CRC screening was partly attenuated to borderline statistical significance (OR = 1.20; 1.00–1.44; Table 3). Occupational class and health-related covariates were not included in the model as they did not exert influence on the estimate for health literacy (Rothman and Greenland, 1998). In the multivariable model, female sex (OR = 1.31; 95% CI: 1.11–1.54) and being in any wealth quintile higher than the poorest (OR = 1.88; 95% CI: 1.43–2.49 for the richest quintile) were positively associated with CRC screening while age was negatively associated (OR = 0.92; 95% CI: 0.91–0.94 per year increase). Results were unaltered in sensitivity analyses removing those who refused to complete the health literacy assessment and those who reported FOBT-based CRC screening outside of England's national programme (not shown).

Discussion

Nearly one in three screening-aged adults lacked adequate health literacy skills in this large sample of older English adults. Limited health literacy was a barrier to participation in FOBT-based CRC screening available through England's National Bowel Cancer Screening Programme. Adults who responded correctly to all items on a four-item comprehension measure of a basic medicine label had 20% greater odds of participating in screening than those who responded incorrectly to at least one item. Younger adults within the screening-eligible age range, women, and those in richer wealth quintiles were also more likely to screen; these factors were stronger predictors of screening than health literacy. However, literacy barriers to screening are modifiable while these demographic factors are either not or not easily modified; hence literacy represents a more feasible intervention target. Given

Table 2
Unadjusted associations between CRC screening, health literacy, and covariates, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Participation in CRC screening				
	Yes (n = 1709; 55%)	No (n = 1378; 45%)	Unadjusted OR (Yes vs. No)	95% CI	p-Value
Health literacy					
Limited	391 (48%)	432 (52%)	1.00		<0.0001
Adequate	1318 (58%)	946 (42%)	1.50	(1.27, 1.78)	
Age					
mean age (SD)	65.8 (3.9)	67.7 (5.1)	0.92[a]	(0.91, 0.94)	<0.0001
Sex					
Male	727 (52%)	668 (48%)	1.00		0.001
Female	982 (58%)	710 (42%)	1.30	(1.12, 1.50)	
Educational attainment					
No qualification	346 (47%)	389 (53%)	1.00		0.0002[b]
Up to degree level	879 (58%)	629 (42%)	1.57	(1.31, 1.89)	
Degree or equivalent	484 (57%)	360 (43%)	1.47	(1.20, 1.82)	
Occupational class					
Routine	640 (53%)	565 (47%)	1.00		0.03[b]
Intermediate	468 (57%)	357 (43%)	1.16	(0.96, 1.29)	
Managerial	593 (57%)	442 (43%)	1.21	(1.02, 1.44)	
Net non-pension wealth fifth					
1 (poorest)	210 (43%)	275 (57%)	1.00		<0.0001[b]
2	324 (57%)	244 (43%)	1.79	(1.39, 2.31)	
3	342 (61%)	221 (39%)	2.08	(1.61, 2.70)	
4	378 (59%)	267 (41%)	1.92	(1.49, 2.46)	
5 (richest)	383 (59%)	264 (41%)	1.96	(1.53, 2.52)	
Ethnicity					
Non-white	34 (44%)	43 (56%)	1.00		0.09
White	1675 (56%)	1335 (44%)	1.55	(0.94, 2.56)	
Limiting longstanding illness					
Yes	512 (51%)	484 (49%)	1.00		0.001
No	1197 (57%)	894 (43%)	1.30	(1.11, 1.53)	
Limited activities of daily living					
Yes	218 (47%)	243 (53%)	1.00		0.001
No	1491 (57%)	1135 (43%)	1.44	(1.17, 1.77)	
Difficulty using the toilet					
Yes	36 (47%)	40 (53%)	1.00		0.21
No	1673 (56%)	1338 (44%)	1.36	(0.85, 2.18)	
Depressive symptoms					
Yes	126 (50%)	126 (50%)	1.00		0.02
No	1563 (56%)	1233 (44%)	1.37	(1.05, 1.80)	
Self-reported general health					
Fair/poor	356 (48%)	385 (52%)	1.00		<0.0001
Excellent/very good/good	1353 (58%)	992 (42%)	1.53	(1.29, 1.82)	
Ever been diagnosed with cancer					
Yes	118 (57%)	89 (43%)	1.00		0.61
No	1591 (55%)	1289 (45%)	0.93	(0.69, 1.25)	

[a] Per one year increase in age.
[b] p-Value for linear trend.

that the NHS primarily communicates CRC screening information through posted written information, interventions that are appropriate for the health literacy skills of screening-aged adults are needed to reduce literacy-based inequalities in CRC screening and to improve overall uptake.

Our findings are consistent with an American study that found lower health literacy, as assessed using a measure of medical vocabulary (the *Rapid Assessment of Adult Literacy in Medicine*; the REALM), was associated with lower self-reported FOBT screening (Arnold et al., 2012). However, two similar studies found no association (Miller et al., 2007; Peterson et al., 2007). One of these studies was statistically underpowered (Peterson et al., 2007), and use of the REALM may have limited all three studies: the REALM simply measures vocabulary, while the decision to undergo FOBT screening is dependent on a broader range of health literacy skills such as comprehension, reasoning, and judgement. Health literacy has, however, been associated with knowledge and positive attitudes toward CRC screening (Arnold et al., 2012; Dolan et al., 2004; Miller et al., 2007; Peterson et al., 2007). The pathways between health literacy, knowledge and beliefs about CRC screening, and screening uptake remain to be elucidated in empirical research, although useful theoretical frameworks exist (Davis et al., 2001; von Wagner et al., 2009b).

Consistent with our findings, an American study of a video intervention to communicate CRC screening information found that individuals with low health literacy were less likely to retain screening information (Wilson et al., 2010). A greater burden of CRC knowledge processing effort during information seeking by those with lower health literacy has also been shown (von Wagner et al., 2009a). Communication interventions to improve CRC screening rates must therefore be appropriate in terms of cognitive and health literacy demands. The current written materials in the NHS screening programme are difficult for individuals to process and understand (Smith et al., 2013), while trials of general practitioner endorsement and 'gist-based' information materials for individuals with low literacy are underway in the UK (Damery et al., 2012; Smith et al., 2013).

Strengths

This large analysis examined the role of health literacy in CRC screening participation in the context of the publicly-available NHS screening programme. Because overall programme uptake remains low and characterised by social inequalities, our results are valuable for understanding and addressing these problems. Although our measure of health literacy was not validated as a stand-alone measure, it was developed

Table 3
The associations between health literacy, covariates, and CRC screening, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Participation in CRC screening	
	Adjusted OR[a] (Yes vs. No)	95% CI
Health literacy		
Limited	1.00	
Adequate	1.20	(1.00, 1.44)
Age		
Per one year increase	0.92	(0.90, 0.94)
Sex		
Male	1.00	
Female	1.34	(1.14, 1.57)
Educational attainment		
No qualification	1.00	
Up to degree level	1.18	(0.96, 1.46)
Degree or equivalent	1.10	(0.87, 1.40)
Net non-pension wealth fifth		
1 (poorest)	1.00	
2	1.86	(1.43, 2.43)
3	2.13	(1.62, 2.80)
4	1.95	(1.50, 2.54)
5 (richest)	1.99	(1.51, 2.61)

[a] Adjusted for health literacy, age, sex, educational attainment, and net non-pension wealth.

using a framework defining literacy as a functional ability to complete goal-directed tasks (Thorn, 2009). This task represents a health management responsibility commonly faced by older adults that requires reading comprehension and judgement skills; this measure is a more comprehensive assessment of functional health literacy skills than simple vocabulary tests such as the REALM. In our statistical analysis we adjusted for important sociodemographic covariates and used population weights to increase the representativeness of our sample to the general English population.

Limitations

The ELSA study is not perfectly representative of the general English screening-eligible population. Only 2% of participants in our study sample were non-white, so we could not assess the impact of ethnicity. Cancer screening questions were delayed during ELSA fieldwork; subsequently, participants in our sample with no educational qualifications, in routine occupations, and in lower wealth quintiles were less likely to receive the cancer screening questions. Receipt of the questions was non-differential by all other variables, including health literacy. We used the appropriate statistical weights to account for differential non-response by these sociodemographic factors (NatCen Social Research, 2012). However, differential responses may still have an impact: participants in these more deprived groups were more likely to have low health literacy and were also less likely to have undergone screening. Finally, our CRC screening data were self-reported, although overall rates of screening were similar to those as recorded by the screening programme database after the first 2.6 million invitations in 2007 (von Wagner et al., 2011). Furthermore, self-report of FOBT screening has been well-validated against medical records in other studies with sensitivities ranging from 80% to 96% and specificities ranging from 71% to 86% (Baier et al., 2000; Gordon et al., 1993; Vernon et al., 2008).

Conclusions

Low literacy is an obstacle to control of colorectal cancer in England. Future research should examine literacy against screening participation rates recorded by the NHS and explore other constructs related to health literacy such as communicative skills and health numeracy. Health literacy interventions for older adults are a priority for improvement in screening rates and reduction in literacy-based inequalities. The potential modifiability of literacy-based screening inequalities relative to broad sociodemographic inequalities represents a route to improvement of health equity in the population that must not be missed by policymakers and the health system. Methods to communicate screening information must be appropriate for the health literacy skills of screening-aged adults. The upcoming introduction of flexible sigmoidoscopy screening in the UK programme provides an opportunity to reduce literacy barriers that should not be overlooked.

Conflict of interest statement

The authors declare that there are no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.ypmed.2013.11.012.

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Appendix 10.2 Predictors of ‘ever’ FOBt screening uptake since 2006

Unadjusted associations between FOBt screening since 2006 and covariates, ELSA

Characteristic	FOBt screening uptake Yes (2995; 70%)	No (1279; 30%)	OR (95% CI)* Yes vs. No
Health literacy			
Low	238 (56%)	186 (44%)	1.00 (ref)
Medium	414 (66%)	213 (34%)	1.52 (1.18, 1.96)
High	2343 (73%)	880 (27%)	2.08 (1.69, 2.56)
Age			
Mean (SD)	65.6 (3.8)	68.2 (4.7)	0.86 (0.85, 0.88)
Sex			
Male	1302 (67%)	637 (33%)	1.00 (ref)
Female	1693 (73%)	642 (27%)	1.29 (1.13, 1.47)
Ethnicity			
Non-white	2932 (70%)	1236 (30%)	1.00 (ref)
White	62 (59%)	43 (41%)	1.65 (1.11, 2.44)
Educational attainment			
No qualification	599 (58%)	426 (42%)	1.00 (ref)
Up to degree level	1530 (73%)	553 (27%)	1.97 (1.68, 2.30)
Degree or equivalent	866 (74%)	300 (26%)	2.06 (1.71, 2.46)
Occupational class			
Routine	1134 (66%)	580 (34%)	1.00 (ref)
Intermediate	775 (71%)	314 (29%)	1.26 (1.07, 1.49)
Managerial	1070 (74%)	317 (26%)	1.48 (1.26, 1.72)
Net non-pension wealth quintile			
1 (poorest)	388 (57%)	289 (43%)	1.00 (ref)
2	540 (69%)	241 (31%)	1.67 (1.35, 2.07)
3	583 (73%)	216 (27%)	2.01 (1.61, 2.50)
4	629 (75%)	214 (25%)	2.19 (1.76, 2.72)
5 (richest)	730 (78%)	210 (22%)	2.59 (2.09, 3.21)
Marital status			
Single	692 (60%)	455 (40%)	1.00 (ref)
Married or living as married	2303 (74%)	824 (26%)	1.84 (1.59, 2.12)
Limiting longstanding illness			
Yes	877 (64%)	2118 (73%)	1.00 (ref)
No	487 (36%)	792 (27%)	1.49 (1.29, 1.70)
ADL limitations			
Yes	397 (63%)	236 (37%)	1.00 (ref)
No	2598 (71%)	1043 (29%)	1.48 (1.24, 1.77)
IADL limitations			
Yes	269 (60%)	179 (40%)	1.00 (ref)
No	2726 (71%)	1100 (29%)	1.65 (1.35, 2.02)
Depressive symptoms			
Yes	713 (65%)	377 (35%)	1.00 (ref)
No	2282 (72%)	902 (28%)	1.34 (1.16, 1.55)
Self-rated general health			
Fair/Poor	577 (60%)	386 (40%)	1.00 (ref)
Excellent/Very good/Good	2418 (73%)	893 (27%)	1.81 (1.56, 2.10)
Self-rated eyesight			
Fair/Poor/Blind	268 (62%)	162 (38%)	1.00 (ref)
Excellent/Very good/Good	2727 (71%)	1117 (29%)	1.48 (1.20, 1.82)
Ever diagnosed with cancer			
Yes	279 (66%)	146 (34%)	1.00 (ref)
No	2716 (71%)	1133 (29%)	1.25 (1.01, 1.55)
Memory (Mean; SD)	15.2 (3.3)	13.7 (3.7)	1.13 (1.11, 1.15)
Verbal fluency (Mean; SD)	6.2 (2.0)	5.5 (2.2)	1.16 (1.12, 1.20)

Appendix 11.1 Paper under peer review at *Am J Prev Med*

Health literacy and the maintenance of moderate-to-vigorous physical activity during aging, 2004 to 2013

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ABSTRACT

Introduction: Health literacy (the ability to read and understand health information) may help to support the long-term maintenance of moderate-to-vigorous physical activity (MVPA) during aging; this relationship has never been examined longitudinally. We aimed to investigate the relationship between health literacy and the maintenance of weekly MVPA over an eight-year period among older adults.

Methods: Data were from interviews with 4345 adults aged 50-79 in the English Longitudinal Study of Ageing from 2004/05 to 2012/13, analyzed in 2015. Health literacy was assessed in 2004/05 as reading comprehension of a medicine label, defined as 'low' (≤2/4 items correct), 'medium' (3/4) and 'high' (4/4). The outcome was maintaining weekly MVPA at all of five time points from 2004/05 to 2012/13. A population-weighted logistic regression model was adjusted for sociodemographic, physical health, and cognitive (memory and verbal fluency) covariates.

Results: Overall, 59% (1840/3128) of participants with high health literacy, compared with 33% (138/420) of those with low health literacy consistently reported weekly MVPA (OR=1.37; 95% CI: 1.04-1.80). Better memory was positively associated with long-term MVPA (OR=1.03; 1.00-1.05 per point increase out of 24), as was better verbal fluency (OR=1.05; 1.01-1.09 per point increase out of 9). Other independent predictors of long-term MVPA included: being male (OR=1.42; 1.23-1.66), having higher education (OR=1.64; 1.33-2.02), being wealthier (OR=3.02; 2.35-3.88), and having no limiting long-standing illness (OR=2.13; 1.77-2.56).

Conclusions: High health literacy and good cognitive function, in addition to indicators of health and social advantage, are independently associated with long-term maintenance of MVPA during aging.

INTRODUCTION

Health literacy is increasingly being recognized as an influence on health,[1,2] and is defined as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions'.[3] According to a national assessment of adult literacy, 10-13% of American adults aged 16-64 and 29% of American adults aged ≥65 have below basic health literacy skills[4] and are often unable to properly self-manage their health.[5–8] Improvement of the health literacy of the population is therefore a goal of the Healthy People 2020 government initiative.[9] Of particular concern are older adults, who are vulnerable to low health literacy due to the negative effects of cognitive aging on health literacy skills.[10–12] At the same time, health literacy is particularly important for the maintenance of health during older age, a time in life when physical, social, and material limitations often increasingly affect one's capacity for health self-management.[13] Indeed, low health literacy has independently been associated with increased risk of all-cause mortality in older adults in several contexts.[14–17]

Health-promoting lifestyle behaviors such as engagement in moderate-to-vigorous physical activity (MPVA) may be mediators on the pathway from health literacy to all-cause mortality risk.[17,18] Low MVPA is robustly and consistently associated with risk of all-cause mortality in older adults.[19–22] Health literacy may positively affect knowledge and attitudes about MVPA and improve self-efficacy to regularly engage in MVPA.[18,23] However, empirical evidence on the relationship between health literacy and MVPA is sparse. An American study of Medicare enrollees and a UK general population survey both found no association between health literacy and weekly physical activity.[24,25] In contrast, an American study of hypertensive patients from federally qualified health centers and a Dutch study of community dwelling adults found that health literacy explained a modest proportion of variance in physical activity behavior, with self-efficacy acting as a mediator.[23,26] Health literacy was also positively associated with engagement in physical activity in the Rush Memory and Aging Project.[27] These studies were cross-sectional and did not adjust for physical or cognitive health, which are major limitations in behavioral studies of health literacy. The potential contribution of cognitive function is particularly salient to consider, given its association with health literacy[11] and emerging relationship with physical function and activity in later life.[28,29]

We aimed to prospectively investigate the association between health literacy and the maintenance of weekly MVPA among older English adults from 2004 to 2013, while accounting for sociodemographic factors, physical health, and cognitive function.

METHODS

Study sample

The English Longitudinal Study of Ageing (ELSA) is a cohort of English adults aged ≥50 years.[30] The ELSA was approved by the London Multicentre Research Ethics Committee (MREC/01/2/91) and informed consent was obtained from all participants. The cohort was established in 2002 based on a random stratified sample of households in England. Data are collected in biennial waves. At present, data from waves 1 to 6 are available, representing 10 years of data collection. The present analysis was conducted in 2015 using data from waves 2 (2004/05) through 6 (2012/13). Eligible participants were non-cognitively impaired ‘core’ ELSA participants aged 50-79 years at wave 2, who completed data collection at all waves with non-proxy interviews (proxy interviews were conducted for institutionalized or physically or cognitively impaired participants). In total, 11392 core participants were interviewed at the ELSA baseline (wave 1). Of these, 4711 remained in the study and completed data collection all waves through wave 6 (41%). Of these, 137 (3%) had proxy interviews in at least one wave, and a further 220 were aged ≥80 years at wave 2 (5%) and were ineligible for this analysis. In total, 4354 participants had completed data at all waves with non-proxy interviews and were aged 50-79 years at wave 2, and were eligible for this analysis.

Measures

Health literacy

Health literacy was assessed in the in-person study interview at wave 2 (2004/05) using a validated four-item measure from the OECD International Adult Literacy Survey and the Adult Literacy and Life Skills Survey.[31] Participants were presented with a fictitious medicine label and were asked four reading comprehension questions (Appendix). Health literacy was scored as ‘high’ (4/4 correct), ‘medium’ (3/4 correct), and ‘low’ (≤2/4 correct).[17] Of the 4354 eligible participants, n=6 refused the assessment and were excluded and n=70 were unable to complete the assessment due to sight, health, or reading problems. The latter individuals were included and coded as having low health literacy, as they would likely perform with low health literacy in real-life settings.[7]

Cognitive function

Aspects of cognitive function that are essential for everyday functioning and sensitive to decline during aging were assessed in a battery in the study interview at wave 2 (2004/05).[32] Aspects of cognitive function that would be minimally affected by literacy skills were included: time orientation (continuous, out of four for the ability to state the correct day, week, month, and year), immediate recall (continuous, out of 10 aurally presented words), delayed recall (continuous, out of the same 10 aurally presented words), and verbal fluency (continuous; the number of animal names listed in one minute). The former three variables were grouped together to create a memory index, with possible scores ranging from 0 to 24.[33] The latter variable was coded as ‘0’, ‘1-7’, ‘8-12’, ‘13-15’, ‘16-17’, ‘18-19’, ‘20-21’, ‘22-24’, ‘25-29’, and ‘≥30’ animals and scored from 0 to 9.[33] A measure of mental processing speed was not included as it required literacy skills by assessing the number of Ps and Qs crossed out in a grid of random alphabet letters.

Moderate-to-vigorous physical activity

Physical activity was assessed in the study interview at each wave, where participants were asked about their typical frequency of participation in mild, moderate, and vigorous sports and activities, with examples given on show cards. Response options were ‘hardly ever or never’, ‘one to three times a month’, ‘once a week’, and ‘more than once a week’. At each wave, physical activity was coded dichotomously as engagement in MVPA once per week or more vs. less than once per week.[22,34] The outcome variable was consistent long-term maintenance of weekly MVPA at every wave from 2004/05 to 2012/13 (yes vs. no).

Covariates

Sociodemographic covariates were assessed in the wave 2 (2004/05) interview: age (continuous), sex (male; female), marital status (married or living as married; single, divorced, or widowed), net non-pension wealth (calculated in quintiles stratified at age 65 to account for the effect of retirement on wealth), educational attainment (degree-level; up to degree-level; no qualifications), and ethnicity (white; non-white). Other covariates were those known to be associated with health literacy or with MVPA in the ELSA: working status (yes vs. no), access to a car when needed (yes vs. no), self-rated health (excellent/very good/good vs. fair/poor), having a limitation in one or more instrumental activity of daily living (IADL; yes vs. no) having a limiting long-standing illness (yes vs. no), presence of depressive symptoms, defined as scoring >4 on the 8-item Centre for Epidemiological Studies Depression Scale (yes vs. no).[35,36]

Statistical analysis

The final sample was 4345/4354, as six participants declined the health literacy assessment and a further three were missing data on physical activity. All other variables were missing on a case-by-case basis. Eight-year maintenance of MVPA was examined bivariately against participant characteristics using frequency counts for categorical variables and means for continuous variables, and unadjusted logistic regression to generate odds ratios (ORs) and 95% confidence intervals (CIs). All covariates were then included in a multivariable-adjusted logistic regression model to predict the relationship between health literacy (‘medium’ vs. ‘low’ and ‘high’ vs. ‘low’) and long-term maintenance of MVPA. With the exception of age, sex, and education, which were forced into the model, all covariates that were not significantly associated with long-term MVPA with $p<0.05$ in the model were removed, as long as their removal did not alter the ORs between health literacy and long-term MVPA by ≥10%.[37] The final model is shown both with and without the cognitive function variables included, to examine the degree to which poor cognitive functioning might explain any relationship between health literacy and MVPA. All regression modeling was performed with population weights applied to account for study non-response and attrition.[38] All statistical analysis was performed using StataSE 13.1 (College Station, Texas)

RESULTS

Table 1 shows the baseline characteristics of the study participants. Engagement in weekly MVPA declined over time in the study population, but decline was more pronounced in adults with low health literacy than in those with high health literacy (Figure 1). Overall, 54% (2350/4345) of participants consistently reported engaging in MVPA at least once per week at all waves (Table 2). This proportion was 59% (1840/3128) among those with 'high' health literacy, 47% (372/797) among those with 'medium' health literacy, and 33% (138/420) among those with 'low' health literacy. The unadjusted OR for eight-year maintenance of MVPA associated with high vs. low health literacy was 2.83 (95% CI: 2.25-3.87). Mean baseline memory and verbal fluency scores were higher among those who maintained MVPA, with unadjusted OR=1.13 (95% CI: 1.11-1.15) per one point memory increase and unadjusted OR=1.21 (95% CI: 1.17-1.25) per one point verbal fluency increase. The other predictors of long-term MVPA in unadjusted models are also shown in Table 2.

The final fully adjusted, population weighted logistic regression models are shown in Table 3. Without memory and verbal fluency in the model, the adjusted OR for eight-year maintenance of MVPA with medium vs. low health literacy was 1.29 (95% CI: 0.95-1.75) and high vs. low was 1.53 (95% CI: 1.16-2.01). With cognitive function in the model, these associations were attenuated by about one-third, to 1.21 (95% CI: 0.89-1.64) for medium vs. low and 1.37 (95% CI: 1.04-1.81) for high vs. low. The OR for memory was 1.03 (95% CI: 1.00-1.05 per point increase) and for verbal fluency was 1.05 (95% CI: 1.01-1.09 per point increase). Other independent predictors of long-term MVPA were: being male (OR=1.42; 95% CI: 1.23-1.66), having degree-level education (OR=1.64; 95% CI: 1.33-2.02), having higher net non-pension wealth (OR=3.02; 95% CI: 2.35-3.88 for the richest vs. poorest quintiles), having good self-rated health (OR=1.76; 95% CI: 1.42-2.18), having no limiting long-standing illness (OR=2.13; 95% CI: 1.77-2.56), having no functional limitations (OR=1.78; 95% CI: 1.46-2.17).

DISCUSSION

In this longitudinal study of older English adults, health literacy was prospectively associated with maintaining MVPA over an eight-year follow-up period. These results are consistent with evidence that health behaviors may contribute to the link between low health literacy and risk of all-cause mortality.[17] Memory and verbal fluency were also positively associated with long-term MVPA, in addition to indicators of social advantage including being male, having degree-level education, being wealthier, and being healthier. These social disparities in the long-term maintenance of MVPA may lead to inequalities in the health outcomes associated with physical inactivity, such as diabetes, heart disease, cancer, and all-cause mortality.[22,39] Further research is needed on the development of health inequalities during the aging process and how they may be prevented. Health literacy, which is modifiable to a degree during aging, may represent a target point.[40]

Our results indicate a graded, rather than a threshold effect of health literacy on engagement in MVPA, consistent with previous research showing a linearly graded relationship between health literacy and physical functioning in older adults.[41] Our results are also consistent with two American studies and a Dutch study of health literacy and physical activity,[23,26,27] but they conflict with an American study of new Medicare enrolees finding null associations between health literacy and several behaviors[24] and a UK study of adults in a younger and wider age range.[25] Our results may differ due to the longitudinal nature of this study, the differing assessment methods for health literacy and MVPA across the studies, and the older age range of our participants. Our results are longitudinal and were adjusted for important aspects of cognitive function that are independent of literacy skills, improving upon previous research in this area.

Our findings that memory and verbal fluency were weakly positively associated with long-term MVPA are consistent with a recent study of older American adults finding that the cognitive functions of task coordination and inhibition of habitual response were associated with physical exercise through self-efficacy.[42] The reverse association, whereby physical activity acts to improve cognitive health in older adults has been well-characterized in a range of prospective cohort studies and randomized controlled trials.[43–46] In a *post-hoc* analysis, we did not observe the reverse association between weekly MVPA at baseline (yes vs. no) and change in memory, verbal fluency, or health literacy over the follow-up (Appendix Table 1). It could be that the association we observed between health literacy and MVPA is explained by unmeasured aspects of cognitive function, such as reasoning. However, in a second *post-hoc* analysis with mental processing speed (an aspect of executive function) included in the final model, it was not associated with long-term MVPA (OR=1.01; 95% CI: 0.97-1.05).

With respect to the social disparities we observed in the long-term maintenance of MVPA, our results are consistent with another study using data from the English Longitudinal Study of Ageing to examine the predictors of sustained physical activity over 10 years,[35] and other cross-sectional and short-term longitudinal studies on the predictors of MVPA in older adults.[47,48] Although physical activity levels are accepted to decline during aging, few studies have examined the sociodemographic and health-related predictors of MVPA over a long follow-up during aging. Our results underscore the role of ability to maintain participation in MVPA over a relatively long time period as a potential mechanism leading to later-life health inequalities. MVPA is important, as physical activity of moderate-to-vigorous intensity is associated with reduced risk for several health outcomes,[39] but it is increasingly difficult to maintain in later life due to increased physical, social, and material limitations.[47] Health literacy may represent a modifiable target for intervention, whereby the maintenance of literacy skills may aid in maintenance of the self-efficacy and level of physical function required to engage in MVPA.[49]

Limitations

MVPA was assessed at multiple time points by self-report and is subject to recall error.[50,51] If recall error in reporting MVPA is non-differential by health literacy, then the odds ratios will be underestimates of the true associations. If the high health literacy group is relatively accurate in reporting MVPA and low health literacy group systematically under-reports (over-reports) MVPA, then our odds ratios will be overestimates (underestimates) of the true association. To the best of our knowledge, there has not been any validation study of self-reported physical activity according to the health literacy of study participants. Overall, the frequency of self-reported MVPA in our sample was slightly higher than that assessed in the population-representative Health Survey for England (HSE), possibly because the longitudinal ELSA sample is slightly healthier and wealthier than the general population of England due to study attrition.[30]

The self-report physical activity assessment used in the ELSA has been validated in a sub-sample of 116 study participants using objective accelerometer data, showing a modest correlation (Spearman's r=0.21; p=0.02).[34] Because of the way the physical activity data were collected in the ELSA, we could not define a variable that mapped directly onto the WHO recommendation of 150 minutes/week of moderate intensity or 75 minutes/week of vigorous intensity, or an equivalent combination of the two.[52] However, the weekly physical activity variables in the ELSA have been associated with a range of health outcomes including all-cause mortality, demonstrating their biological and clinical relevance.[22,34]

The health literacy measure used in this study was validated,[31] but displayed a ceiling effect that is common to other standard measures of functional health literacy.[53,54] However, the measure has predictive ability for important health outcomes including the uptake of preventive health services and risk of all-cause mortality in older adults.[7,17] Another limitation is that attrition was differential by baseline wealth, as 15% of participants who remained in the study up to wave 6 were in quintile 1 (poorest) and 24% were in quintile 5 (richest); if no attrition occurred these proportions would be 20%. We have likely underestimated the association between net non-pension wealth and the long-term maintenance of MVPA. Participants with low health literacy and no educational qualifications were also more likely to drop out of the study; we may have underestimated the true associations between these variables and long-term MVPA.

Despite these limitations, this is the first study that we are aware of to simultaneously examine the roles of health literacy and cognitive function in contributing to the long-term maintenance of MVPA during aging. Strengths of this study include its large sample size and longitudinal nature, as health literacy measurements with follow-up data are rare, especially for an eight-year period as in the present study. The ELSA is one of the first available data sources that can investigate the behavioral outcomes of health literacy, especially jointly with other sociodemographic and health-related factors. We applied representative population weights to our regression models to account for differential degrees of non-response and attrition across population subgroups.[38]

Conclusions

Health literacy and cognitive function had independent positive associations with the long-term maintenance of MVPA in this prospective cohort of older English adults. These factors may be useful markers of capacity for maintenance of this health-promoting lifestyle behavior in older adults. However, there were marked social inequalities in the long-term maintenance of MVPA during aging. Adults who were male, highly educated, wealthier, and healthier were the most likely to maintain MVPA over the eight-year follow-up period. These long-term patterns of MVPA may translate to social inequalities in health outcomes. Further research is needed on how the trajectories of health behaviors during aging may contribute to health inequalities among older adults.

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Table 1. Characteristics of the sample, England, 2004-13, n=4345

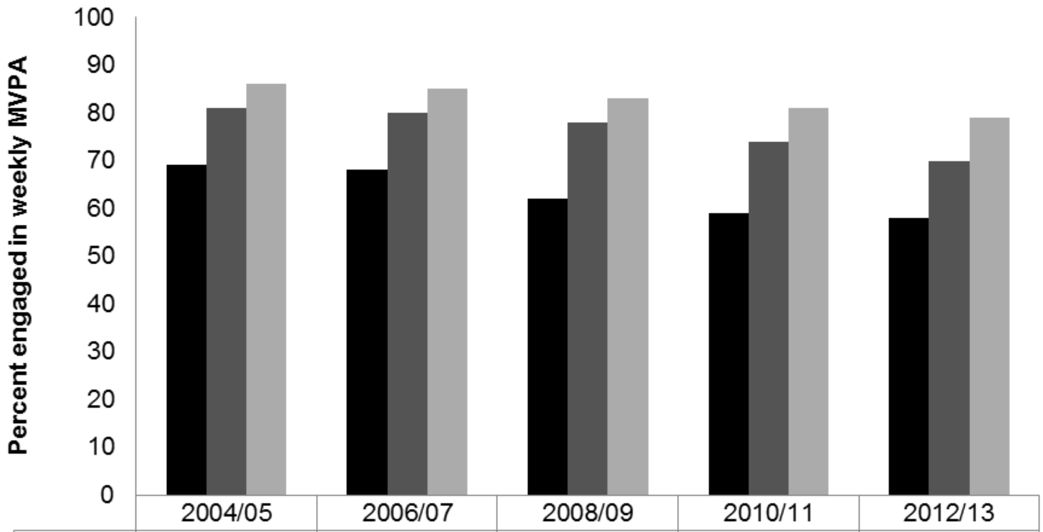
Characteristic	N (%)
Age (n=4345)	
Mean (SD)	63.28 (7.26)
Sex (=4345)	
Female	2432 (56%)
Male	1913 (44%)
Ethnicity (n=4344)	
Non-white	79 (2%)
White	4265 (98%)
Educational attainment (n=4344)	
No qualification	1275 (29%)
Up to degree level	1988 (46%)
Degree level	1081 (25%)
Net non-pension wealth quintile (n=4130)	
1 (poorest)	625 (15%)
2	767 (19%)
3	854 (21%)
4	875 (21%)
5 (richest)	1009 (24%)
Working status (n=4345)	
Not working	2603 (60%)
Working	1742 (40%)
Marital status (n=4345)	
Single	1183 (27%)
Married or living as married	3162 (73%)
Access to a car when needed (n=4345)	
No	514 (12%)
Yes	3831 (88%)
Self-rated health (n=4344)	
Fair/poor	905 (21%)
Excellent/very good/good	3439 (79%)
Limiting long-standing illness (n=4345)	
Yes	1258 (29%)
No	3087 (71%)
Any IADL limitations (n=4345)	
Yes	952 (22%)
No	3393 (78%)
Depressive symptoms (n=4345)	
Yes	382 (9%)
No	3963 (91%)
Health literacy (n=4345)	
Low	420 (10%)
Medium	797 (18%)
High	3128 (72%)
Memory score (n=4337)	
Mean (SD)	14.70 (3.23)
Range	0 - 24
Verbal fluency score (n=4344)	
Mean (SD)	5.93 (2.07)
Range	0 - 9

Table 2. Unadjusted associations between participant characteristics and MVPA, England, 2004-13

Characteristic	Eight-year maintenance of MVPA (Yes vs. No)			
	Yes (n=2350; 54%)	No (n=1995; 46%)	OR[a]	95% CI
Age (n=4345)				
Mean (SD)	61.91 (6.54)	64.90 (7.72)	0.94	(0.93, 0.95)
Sex (n=4345)				
Female	1200 (49%)	1232 (51%)	1.00	
Male	1200 (60%)	763 (40%)	1.55	(1.36, 1.76)
Ethnicity (n=4344)				
Non-white	29 (37%)	50 (63%)	1.00	
White	2320 (54%)	1945 (46%)	2.30	(1.40, 3.81)
Educational attainment (n=4344)				
No qualification	485 (38%)	790 (62%)	1.00	
Up to degree level	1152 (58%)	836 (42%)	2.28	(1.97, 2.65)
Degree level	713 (66%)	368 (34%)	3.11	(2.61, 3.71)
Net non-pension wealth quintile (n=4130)				
1 (poorest)	212 (34%)	413 (66%)	1.00	
2	355 (46%)	412 (54%)	1.74	(1.38, 2.18)
3	457 (54%)	397 (46%)	2.29	(1.83, 2.86)
4	538 (62%)	337 (39%)	3.32	(2.65, 4.16)
5 (richest)	703 (70%)	306 (30%)	4.57	(3.65, 5.71)
Working status (n=4345)				
Not working	1197 (46%)	1406 (54%)	1.00	
Working	1153 (66%)	589 (34%)	2.45	(2.15, 2.79)
Marital status (n=4345)				
Single	504 (43%)	679 (57%)	1.00	
Married or living as married	1846 (58%)	1316 (42%)	2.03	(1.76, 2.33)
Access to a car when needed (n=4345)				
No	160 (31%)	354 (69%)	1.00	
Yes	2190 (57%)	1641 (43%)	3.03	(2.46, 3.73)
Self-rated health (n=4344)				
Fair/poor	247 (27%)	658 (73%)	1.00	
Excellent/very good/good	2103 (61%)	1336 (39%)	4.43	(3.74, 5.24)
Limiting long-standing illness (n=4345)				
Yes	399 (32%)	859 (68%)	1.00	
No	1951 (63%)	1136 (37%)	3.97	(3.44, 4.59)
Any IADL limitations (n=4345)				
Yes	263 (28%)	689 (72%)	1.00	
No	2087 (62%)	1306 (39%)	4.28	(3.63, 5.05)
Depressive symptoms (n=4345)				
Yes	144 (38%)	238 (62%)	1.00	
No	2206 (56%)	1757 (44%)	2.03	(1.61, 2.55)
Health literacy (n=4345)				
Low	138 (33%)	282 (67%)	1.00	
Medium	372 (47%)	425 (53%)	1.83	(1.41, 2.37)
High	1840 (59%)	1288 (41%)	2.83	(2.25, 3.57)
Memory score (n=4337)				
Mean (SD)	15.25 (3.05)	14.06 (3.31)	1.13	(1.11, 1.15)
Verbal fluency score (n=4340)				
Mean (SD)	6.23 (2.11)	5.52 (2.11)	1.21	(1.17, 1.25)

Table 3. Adjusted odds ratios for eight-year maintenance of MVPA, England, 2004-13

Characteristic	Eight-year maintenance of MVPA (Yes vs. No)			
	OR[a]	95% CI	OR[b]	95% CI
Age				
Per year increase	0.94	(0.93, 0.95)	0.95	(0.94, 0.96)
Sex				
Female	1.00		1.00	
Male	1.39	(1.20, 1.60)	1.42	(1.23, 1.66)
Educational attainment				
No qualification	1.00		1.00	
Up to degree level	1.31	(1.10, 1.57)	1.24	(1.04, 1.49)
Degree level	1.74	(1.41, 2.14)	1.64	(1.33, 2.02)
Net non-pension wealth quintile				
1 (poorest)	1.00		1.00	
2	1.54	(1.20, 1.98)	1.52	(1.18, 1.96)
3	1.78	(1.39, 2.28)	1.73	(1.35, 2.21)
4	2.59	(2.02, 3.32)	2.50	(1.95, 3.21)
5 (richest)	3.19	(2.49, 4.09)	3.02	(2.35, 3.88)
Self-rated health				
Fair/poor	1.00		1.00	
Excellent/very good/good	1.83	(1.48, 2.26)	1.76	(1.42, 2.18)
Limiting long-standing illness				
Yes	1.00		1.00	
No	2.11	(1.76, 2.54)	2.13	(1.77, 2.56)
Any IADL limitations				
Yes	1.00		1.00	
No	1.78	(1.46, 2.17)	1.78	(1.46, 2.17)
Health literacy				
Low	1.00		1.00	
Medium	1.29	(0.95, 1.75)	1.21	(0.89, 1.64)
High	1.53	(1.16, 2.01)	1.37	(1.04, 1.81)
Memory score				
Per point increase	-	-	1.03	(1.00, 1.05)
Verbal fluency score				
Per point increase	-	-	1.05	(1.01, 1.09)



	2004/05	2006/07	2008/09	2010/11	2012/13
Low	69	68	62	59	58
Medium	81	80	78	74	70
High	86	85	83	81	79

Figure 1. Engagement in weekly MVPA at each time point (%), according to baseline health literacy

APPENDIX

Appendix Table 1. Reverse associations between baseline MVPA and change in memory, verbal fluency, and health literacy over the follow-up, England, 2004-13, n=4345

MVPA	Health literacy decline of ≥1 point (Yes vs. No)	Memory decline of >1 point (Yes vs. No)	Verbal fluency decline of >1 point (Yes vs. No)
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Weekly MVPA at baseline			
No	1.00 (ref)	1.00 (ref)	1.00 (ref)
Yes	0.93 (0.73, 1.17)	0.93 (0.76, 1.13)	0.99 (0.82, 1.20)

Note: All ORs adjusted for age, sex, ethnicity, education, net non-pension wealth, self-rated health, limiting long-standing illness, and IADL limitations, and are population-weighted

Appendix 11.2 Physical activity show card

P3096 HEACTA/HEACTB/HEACTC

CARD C25

Vigorous	**Moderate**	**Mild**
For example:	*For example:*	*For example:*
Running or jogging	Gardening	Vacuuming
Swimming	Cleaning the car	Laundry
Cycling	Walking at a moderate pace	Home repairs
Aerobics or gym workout	Dancing	
Tennis	Floor or stretching exercises	
Digging with a spade or shovel		

Appendix 11.3 Fruit and vegetable intake assessment

36 **Using the measures below, how much of the following did you eat yesterday?**
Please read through the whole list before answering.
For each food type, write '0' if none eaten.

	Write in number	
Salad (cereal bowlfuls)		228-229
Tablespoons of vegetables (raw, cooked, frozen or tinned) *Include peas and greens. Do not include potatoes*		230-231
Tablespoons of pulses such as baked beans, red kidney beans, lentils		232-233
Tablespoons of other dishes mainly made from vegetables or pulses, such as vegetable lasagne or vegetable curry		234-235

37 **Using the measures below, how much of the following did you eat yesterday?**
Please read through the whole list before answering.
For each food type, write '0' if none eaten.

	Write in number	
Average handfuls of very small fruit, such as grapes, berries		236-237
Small fruit, such as plums, satsumas		238-239
Medium fruit, such as apples, bananas, oranges		240-241
Half a large fruit, such as grapefruit		242-243
Average slices of a very large fruit, such as melon		244-245
Tablespoons of frozen or tinned fruit		246-247
Tablespoons of dried fruit, such as raisins, apricots		248-249
Tablespoons of other dishes made mainly from fruit such as fruit salad or fruit pies		250-251
Small glasses of fruit juice		252-253

Fruit and vegetable intake was assessed in the self-completion questionnaire using the above questions at each of waves three and four. The responses were summed and dichotomised to be <5 vs. ≥5 servings in the past day.

40 **How many portions of vegetables – excluding potatoes – do you eat on a typical day?**
If none, please enter ‘0’.
A serving or portion of vegetables means three heaped tablespoons of green or root vegetables such as carrots, parsnips, spinach, small vegetables like peas, baked beans or sweet corn, or a medium bowl of salad (lettuce, tomatoes, etc).

Please write in portion ☐ 299-300

How many portions of fruit – of any kind – do you eat on a typical day?
If none, please enter ‘0’.
A portion of fruit is an apple or banana, a small bowl of grapes, or three tablespoons of tinned or stewed fruit. If you drink fruit juice, you can count one glass per day, but additional glasses of fruit juice do not count as additional portions.

Please write in portion ☐ 301-302

Fruit and vegetable intake was assessed in the self-completion questionnaire using the above questions at waves 5 and 6. The responses were summed and dichotomised to represent <5 vs. ≥5 servings on a typical day.